

Employment without barriers

Employment that works
for people with MS

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All-Party Parliamentary
Group for MS

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About Multiple Sclerosis (MS)

MS is a neurological condition that affects more than 130,000 people in the UK. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how people walk, move, see, think and feel.

About the All-Party Parliamentary Group (APPG) for MS

The APPG for MS is a cross-party group of Parliamentarians in Westminster committed to tackling issues affecting people with MS. The group is made up of MPs and Peers from all parties who help to make sure MS issues are high on the Government's agenda. The MS Society is the secretariat of the group and provides both administrative and financial support for the group's work.

Foreword from Simon Hoare MP

The COVID-19 pandemic has marked a huge change in the way people work. Many have switched to working remotely, while others have experienced furlough or sadly lost their jobs. Employers have had to consider their employees' needs and lives outside of work and adapt to this. While the jobs market is now recovering, the last two years have shown that employment is key to people's lives, their identity, and for many, a vital part of staying connected with others.

Some people with MS have benefitted from more flexible working, helping them to better manage their symptoms. But there are still far too many who don't get the support they need to move into and remain in high-quality employment. The employment rate for people with MS is 41%, while for non-disabled people it is 81%. This can be due to a lack of effective support to help them find suitable work or not being supported to thrive in their roles.

The APPG for MS felt that now is a pivotal time to assess the experiences of people with MS in employment, and make recommendations to improve support and outcomes for those living with MS.

To support the inquiry, we established a design group – a group of experts by experience who shaped this report. I would like to thank the group for attending multiple meetings and for sharing their insights over the last year.



“During the inquiry, I've been struck and at times disheartened by how many people with MS have remarked that they feel ‘lucky’ to simply be in their jobs.”

We held a series of roundtables and focus groups to understand the world of work for people with MS. We uncovered examples of good practice, but also areas where government and employers can improve. We heard about employers working hard to support their employee's needs. But, sadly, also employers failing to support people with MS with the smallest of requests.

This report explores the employment journey across three key areas: looking for and moving into work; staying in work; and leaving work. It includes recommendations on how people with MS can be supported to find and move into suitable jobs, stay in work for as long as is right for them, and leave work in a dignified way.

As the Government develops its plans to reform welfare and reduce the disability employment gap by supporting a million more disabled people in work in the decade to 2027, we hope it listens to the recommendations in this report.

During the inquiry, I've been struck and at times disheartened by how many people with MS have remarked that they feel 'lucky' to simply be in their jobs. Often, they are the best candidate for the role – with all the qualifications, skills and characteristics required to excel in the position.

It's their employers that should feel lucky to have them.

Simon Hoare MP, Chair

All-Party Parliamentary Group for MS

41%

of people with MS
are in employment

81%

of non-disabled people
are in employment

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Executive summary

Most people with MS start experiencing symptoms during the peak of their working lives, and 80% retire within 15 years of their diagnosis.¹ Many say leaving work was the right thing to do, usually because their MS symptoms had made working too hard. But sadly, others were forced to exit their job earlier than they wanted to. This was often because they could not get the support they needed from their employer or the Government to stay in work, and return to work from disability-related absence. The Government and employers need to improve the support they provide to help people with MS stay in work for as long as is right for them.

People with MS who are unemployed can find it hard to get into the job market. Those currently in work sometimes give up looking to take the next step in their career. This is not for lack of trying. People with MS often do not have the right support, including from the Government, to find suitable work. They can struggle to find jobs with employers who understand their condition, and who will support them.

For those who choose to leave work altogether, the decision can be challenging for people with MS, where they have to weigh up their health needs with financial and emotional worries. Sadly, too many people have not been able to leave work when it suited them, in a way that worked for them. Often this was because they did not get the right support from their employer or the Government. Having an unsuccessful exit from work can be distressing for people with MS, where they may struggle with their mental health, experience a big drop in income and

In the past 12 months, have you received support to remain in employment?

44%

No, and I have not needed support

25%

Not applicable

20%

Yes

1%

I am not sure

their symptoms may get worse. But it does not need to be this way. The Government and employers need to make sure people with MS get the support they need to move out of work successfully and with dignity.

People with MS also face barriers in many other areas of their life – not directly linked to employment - but which negatively affect their employment outcomes. These include a lack of access to appropriate health services, and social care; not enough support for unpaid carers; a lack of accessible, adaptable, and affordable homes; insufficient financial support to cover the extra costs of living with MS, made worse by a stressful and complex benefits system; and a digital divide where some people don't have the digital skills or access to devices available to others.

To help people with MS find, move into, stay in and move out of work, the Government needs to reduce barriers in these areas as well as focusing on those more directly linked to employment.

Recommendations

Looking for and moving into work

- The Government should **improve Jobcentre services** for helping people with MS find work by giving better training, increasing the number of Disability Employment Advisors (DEAs) and providing people with MS information on the support they can get in the workplace.
- The Government should **increase the scale, quality and awareness of employment support programmes** helping disabled people into work. This could be done by increasing funding for smaller, local organisation as well as for the Intensive Personalised Employment Support (IPES) scheme.
- The Government should **change Access to Work** so it supports disabled people to move into work. Disabled people looking for jobs should be given indicative awards in advance of starting work. The 'Adjustments Passport' should be extended to everyone, and employers and potential employees should have the opportunity to discuss what could be available through the scheme during the recruitment process.
- The Government should legally require all employers to give their employees the **option to work flexibly from day one of their employment**. This should be unless the employer has a credible business reason not to do so.
- The Government should **strengthen the Disability Confident scheme** by bringing in mandatory reporting for all employers. The scheme should ensure that employers on the scheme meet minimum thresholds for the percentage of disabled people in their workforce.

Staying in work

- The Government should **set up a 'one-stop shop' of information and advice** for employers and employees to help them understand how disabled people, and people with MS can be supported at work.
- The Government should **make sure employers make reasonable adjustments** for people with MS by taking stronger action against employers who fail to put them in place. The Government should also **strengthen the Equality Act duty**, by making employers provide a written response to employees' requests within two weeks. **People with MS should be helped to assert their legal rights** which could be done by reversing legal aid cuts and reducing delays in the Employment Tribunals system.
- The Government should **improve Access to Work** so it supports disabled people to stay in work. The application and renewal process must be improved, and delays reduced. Assessments should be more holistic and more needs to be done to raise awareness of the scheme.
- The Government should strengthen the statutory sick pay (SSP) system so it can support people with MS to stay in work. It must take forward the proposals in Health is Everyone's Business (HIEB) and extend the proposal for flexible SSP to people who need a phased exit from work. **SSP should be available from day one of absence**, and the rate increased.
- Employers should follow **policies to support disabled people to return to work** from absence. They should make sure they provide structured support to help employees return to the workplace following recommendations from their health care professionals. There should be a range of options available to the employee to ease them back into their role. Disability related leave should be treated differently to sick leave.

Leaving work

- Employers should follow **policies to support people with MS to have a dignified exit from work, when it is right for them.** They should consider all reasonable adjustments that could allow for someone to have a phased exit from work and have ongoing conversations with the employee during this time. Employers should **provide careers advice, counselling, and support to access out of work benefits.**
- Employers and the Government should **improve support given to disabled people to help them access benefits and support** once they have left work. This could be through giving employees information and advice on benefits and support, and signposting to more advice. The Government should provide clear advice through a one-stop shop and make sure everyone who starts a claim for a disability benefit is given a single point of contact in the DWP.
- The Government should **make sure the welfare system provides adequate and appropriate support to those who cannot work due to their MS.** The criteria for the Work Capability Assessment (WCA) should be changed. Staff working for the DWP should always treat people with empathy, dignity and respect. Finally, **benefit rates should be set at a level that means all disabled people, including people with MS, can cover their costs and live independent lives.**

About the report

Methodology

The lived experience and insights of people with MS form the basis for this inquiry. A 'design group' was established to help develop and draft this report. This group was made up of a small number of people with MS, from a range of backgrounds. They shared their experiences of employment and provided valuable insight. The recommendations in this report were co-designed with the input of this group.

Throughout the APPG inquiry, 3 virtual focus groups were held with 12 people with MS. In these they talked about the barriers they had faced to employment, primarily in the three main areas of focus of this report. A number of informal one-to-one conversations took place with people with MS where they talked about similar themes.

Desk-based research was also conducted. This primarily reviewed data and evidence from reports looking at the barriers to employment for people with MS and disabled people. It considered government proposals for measures to be taken to improve the employment outcomes of people with MS.

Devolved nations

This report talks about the barriers people with MS face to finding, moving into, staying in, and moving out of work. It makes a number of recommendations for how the Government should reduce these barriers. Unless otherwise specified, the barriers affect people with MS living and working across the UK, and the recommendations are relevant to all nations of the UK.

COVID-19 pandemic

This report explores the barriers to employment that have affected people with MS over many years, and does not take a COVID-19-specific view of employment. Most people with MS who took part in this inquiry shared insights from across all their years of experience in employment. Much of this predated the pandemic, and is not unique to the world of work during this time. Nevertheless, the report does talk about some of the distinct employment-related developments that have occurred during the pandemic, and how these have affected people with MS. For example, the increase in flexible and remote working.

01

Looking for and moving into work

Looking for a new job can be a difficult time. We may worry we can't find a role that is secure or that pays enough for us to cover our bills. And if we are lucky enough to be offered a job, we might then worry about settling into our new workplace. We may wonder if we will get along with our new colleagues and manager, and have doubts about our ability to do the job.

Like everyone else, these worries will be familiar to people with MS. But people with MS have the added pressure of going through this process with the worry their potential employer may not understand how their condition affects them and may not do enough to support them. They also have to cope with looking for jobs in a society where there is not enough effective support to help them find and move into suitable work.

This section explores the main barriers people with MS said they experience when looking for and moving into work. And it recommends steps the Government and employers should take to improve in this area.

People with MS lack effective support to help them find work

Jobcentre Plus services

Jobcentre Plus, part of the DWP, is the main government agency helping people find work. People with MS who are unemployed and looking for a job, or who have been unemployed in the past, are likely to have been in contact with the Jobcentre at some point in their employment journey. However, this service is not trusted by many people with MS, and it fails to give them the support they need to find suitable work.

Some people with MS said they had negative experiences while using Jobcentre services. Jobcentre support was too general and the staff often lacked an understanding of MS, and of individual needs and circumstances. This led to people being told to apply for jobs unsuitable for them, including roles that were too physically demanding or were not right for their experience and work history. People with MS were also disappointed at the lack of advice and information available about extra support to help them in the workplace, such as reasonable adjustments, access to government schemes, and financial support.

The Jobcentre's main focus is on helping unemployed people find work and it does not do a lot to support those currently in work who are searching for jobs. Most people with MS who are out of work are unable to work due to their condition. Only around 1 to 2% of people with MS who are of working age are out of work and looking for work.² So it is no surprise people with MS currently in work and searching for their next

Recommendation

The Government should improve Jobcentre services for helping people with MS find work:

- Give better training to work coaches so they can give appropriate support to people with MS to find suitable work
- Increase the number of Disability Employment Advisors (DEAs) to make sure all people with MS can access their support if they want it
- Make sure people with MS using Jobcentre services are given information and advice on the extra support they can get in the workplace

job said they see the available support as having little relevance for them.

All of this leads to low trust in the Jobcentre amongst people with MS. This is only made worse by a widespread perceived agenda of cuts and other negative experiences people have had while accessing DWP services. These include distressing assessments for benefits such as Personal Independence Payment (PIP) and Employment and Support Allowance (ESA). Some people with MS even said they chose not to apply for disability benefits so they could avoid having to deal with the Jobcentre.

The DWP needs to make improvements to the services it provides to people with MS to help them find work. It should make sure the Jobcentre is seen as a welcoming service supporting all people with MS, whether in or out of work, and at all levels of employment.

Any person with MS visiting the Jobcentre to look for a job will be assigned a work coach, a DWP staff member who supports them to find employment. Work coaches should not be expected to be experts in MS. However, as they are the main point of contact in the Jobcentre for people with MS looking for work, they do need better support so they can support people with MS appropriately. They need better information and training so they can understand the barriers to employment people with MS face, including how their condition may affect them in the workplace and the types of jobs they can do.

Disability Employment Advisors (DEAs) should play more of a role in helping people with MS looking for work, and to assist work coaches. DEAs are DWP staff who specialise in advising disabled people on looking for jobs and gaining new skills. It is welcome the Government has increased the number of DEAs. However, this increase is still too low, given demand

“I constantly get passed around talking to lots of different people. They need someone who understands disability and how reasonable adjustments, Access to Work, and support work operates.”

“There is support but it needs to be more flexible and more individual. The people that are in front of you at the Jobcentre are trying to do their best, by following a process, but unfortunately some people don't fit.”

for their support has increased during the COVID-19 pandemic with a high number of disabled people falling out of work.³ There are around 1100 DEAs currently working in Jobcentres.⁴ This is compared to 366,000 unemployed disabled people.⁵ This means there is only one DEA for every 332 unemployed disabled people. The Government should increase the number of DEAs to a level that guarantees all people with MS looking for work can access support from a DEA if they need it.

All staff working in Jobcentres need to take a compassionate approach to helping people. And one that is tailored to the specific needs, work experience and skills of the person looking for work. More information and advice also needs to be given to people with MS using Jobcentre services around the extra support they can get in the workplace, such as reasonable adjustments.

Employment support programmes

Over the years, the Government has set up a number of national programmes to help disabled people get into work. Many people with MS have been unable to benefit from the support on offer. This is often due to not being eligible, being unaware the programmes even exist, or not finding them effective for helping them to get into suitable work or progress in their careers.⁶

The Government's employment support programmes do not have a lot of success in helping disabled people to move into work. For example, the latest evidence shows only 22% of people taking part in the Government's main employment support programme for disabled people in England and Wales, the Work and Health Programme, have achieved a 'job outcome' within 24 months.⁷ Some people with MS said these programmes do not adopt enough of a tailored or holistic approach. This is an approach that is responsive to their specific skills and circumstances, and which would help them to deal with wider barriers they face to employment. The programmes offer little advice on how people with MS can be supported in the workplace, such as information on reasonable adjustments, or access to government support schemes. People with MS also said there is a lack of specialised careers advice available, which helps to match them to suitable jobs.

The Government should redesign its employment support for disabled people. This should include moving away from the general, national-level approach it currently takes. There are many local organisations across the country offering specialised employment support to disabled people. These organisations are often better placed than national schemes to support people with MS to find suitable work. This is because they are more likely to be connected with the local employment market and

Recommendation

The Government should increase the scale, quality and awareness of programmes aimed at helping disabled people into work:

- Increase funding for smaller, local organisations and schemes giving specialised employment support to people with MS
- Increase funding for the Government's Intensive Personalised Employment Support (IPES) scheme so places can be offered to all people with MS who would benefit from its intensive, tailored support

wider local services, and usually take a more holistic approach which looks at helping people tackle the wider complex barriers they may face to getting into work. However, these local projects often find it difficult to access funding from the Government or win contracts, meaning too few people with MS can access this specialised local support.

It is welcome the DWP has committed to funding a 'local supported employment trailblazer' in England, Scotland and Wales in the Government's National Disability Strategy.⁸ However, the scheme will only support approximately 1,200 people, which means only a tiny proportion of the 366,000 unemployed disabled people will be able to participate. The Government needs to greatly increase funding for smaller, more specialised organisations and schemes operating at a local level. Funding should be increased to a level that allows all people with MS to access specialised employment support in their local area if they want to.

The Government's Intensive Personalised Employment Support (IPES) scheme in England and Wales does seem to take a better approach to supporting disabled people in suitable work than some previous national schemes.⁹ People in this scheme get intensive one-to-one support tailored to their needs, helping them to overcome the barriers they face to employment. The scheme is only expected to support around 10,000 unemployed disabled people.¹⁰ So it is unlikely many unemployed people with MS will be able to access it. Funding levels need to be increased to make sure places can be offered to all unemployed people with MS who would benefit from the intensive, tailored support of the scheme. There should also be regular evaluations of the scheme and how it can be improved.

The Government should encourage employment support providers to offer more careers advice, and information around the support people with MS can get in the workplace, such as reasonable adjustments. There needs to be better joint working with other providers, and improved signposting and referral systems, so people with MS can access wider support they need more easily.

People with MS worry their potential employer will not support them

People with MS experience a number of worries and doubts when thinking about which jobs to apply for. These can be a major barrier to people with MS being able to move into jobs which are right for them or progress in their careers.

People with MS often wonder if they will feel comfortable disclosing their MS with the potential employer. They may worry about the employer not being understanding of their condition and be concerned they will be made to feel 'different' or like a 'special case' if they do disclose. They may also fear the workplace as a whole will not be inclusive of disabled people.

They have to consider about whether the employer will be understanding of the support they may need in the workplace and whether they will actually give them this support. People with MS may not know what support they can get when they do take up a new role, including their legal rights. And those who are currently in work who are well supported by their employer said they felt worried about risking losing their support if they were to move into a new job with a new employer.

All these worries do not exist in a vacuum. People with MS have them because they are aware there are far too few employers who understand MS or do enough to support them in the workplace. This means people with MS cannot be certain of whether the job they are going for is with an employer who will be supportive or not. This places people with MS in a state of insecurity when they are considering job opportunities.

“I now see disclosing as a step toward partnership with my employer, however I can understand why many are so reluctant to raise their heads above the parapet, as there is a huge amount of blind faith involved on our part.”

“I am scared of trying to get a new job, and the fear of how another employer may see my MS, or not support me, prevents me from trying to get a new job. I feel I'm at exactly the same level as when I started my job 17 years ago.”

Too many employers failing to understand MS or support their employees - and the resulting doubt and worries felt by people with MS looking for work - is influenced by a number of factors.

Access to Work

The Government's Access to Work scheme is a grant scheme giving support to disabled people to help them remain in work.¹¹ It is a positive scheme helping many disabled people, including people with MS at work. However awareness of this support is still relatively low and there are issues with the application, renewal and assessment processes. The section of this report 'Staying in work' sets out how the Government can improve these processes and raise awareness of the scheme.

It is only once an employee starts work they are assessed by Access to Work and given support. People with MS who are job hunting, or their potential employers, do not know what support they may get from Access to Work, before they start work. This means even in situations where Access to Work will fund the support the person with MS will need once they move into work, they may be reluctant to apply for a job if they do not know the support they can get. An employer may also be reluctant to employ them as they may be worried about the costs and difficulties taking on the person with MS could lead to. This is without the advance knowledge the scheme will fund the potential employee's support needs.

The Government should give disabled people who are looking for work 'in principle' indicative awards from Access to Work. These awards would let people know in advance of starting work what support they will get. This would give people with MS more

Recommendation

The Government should improve Access to Work so it supports people with MS to move into work:

- Give disabled people who are looking for work 'in principle' indicative awards from the scheme, which would let them know in advance of starting work what support they will get
- Extend the new 'Adjustments Passport' to everyone who receives support from Access to Work
- Allow employees and employers the opportunity to explore, before and during the recruitment process, what support might be available from the scheme once someone starts a new job

confidence ahead of starting a new role that they will be supported in the way they need once they start work.

The new Access to Work 'Adjustments Passport' should also be extended to anyone who receives support from Access to Work. The passport gives an overview for employers of the possible support available from Access to Work for a new employee.¹² However, it is currently only being trialed with young people transitioning from education to work, or vice versa, veterans leaving the armed forces and contractors moving between job roles. Extending the passport to everyone who receives Access to Work funding would help make conversations about adjustments with potential employers easier for all employees with MS. It would also reduce the need for reassessments and lower the risk of a delay to starting a new job.

More employers should be proactively reaching out to all potential employees before and during the recruitment process to explore what support they may need once they start work. Access to Work could add value to these conversations. It could give employers, potential employees and the scheme the opportunity to have a three-way discussion around what support Access to Work could give once the employee starts. And state how soon adjustments could be put in place. Having these conversations could help to reduce concerns over the cost of adjustments for the employer and give the employee more confidence they will get the support they need.

While section 60 of the Equality Act¹³ would prevent employers from proactively asking about someone's health and disability, if our other recommendations were implemented in full many more employees would feel confident to raise this proactively. The Government should also make sure enabling conversations with the scheme during the recruitment process would not have the unintended consequence of making the recruitment process much longer for a disabled person in comparison to someone who is not disabled.

Flexible working

Many people with MS find flexible working is an adjustment that can benefit them greatly. This includes having later starting times, working condensed hours and working from home, allowing people to better manage their symptoms. While more people have been able to work flexibly since the start of the COVID-19 pandemic, there are some who have not been able to work in this way, despite wanting to. This is sometimes even where there is not a good reason for their employer to not let them.

People have the right to request flexible working, but only after they have worked for their employer for over 26 weeks.¹⁴ Employers can refuse the request if they have a business reason to do so, and some people are not even aware they can make such a request. Others are worried about making the request in the first place as they may be worried their employer will think they are making a fuss.

It is welcome the Government is running consultation on giving employees the right to request flexible working from day one of their employment.¹⁵ However, this policy would place the onus on people to be aware they have this right in the first place. And it does not give people looking for work with any guarantee a potential employer would accept their request.

The Government needs to give people with MS more confidence they can work flexibly in their new or potential role. To do this, it should make sure, as a legal default, all employees, in all jobs, are given the option to work flexibly by their employer from day one of their employment. This should be unless their employer has a credible business reason to not do so. This would shift the onus away from the employee having to be aware they can make a request - and having the confidence to do so - and onto the employer to show working flexibly was not possible.

Recommendation

The Government should legally require all employers to give their employees the option to work flexibly from day one of their employment. This should be unless the employer has a credible reason not to do so.

Disability Confident

'Disability Confident' is the Government's main scheme aimed at encouraging employers to recruit, and retain, disabled people as employees. By signing up to the scheme, employers agree to a number of commitments, including being more inclusive and accessible with how they recruit. Employers on the scheme can move up through levels on the scheme by meeting their commitments. And can display a badge on their website and other promotional materials showing they are a 'Disability Confident' employer.¹⁶

Some people with MS said they look out for this badge on potential employers' promotional materials, helping them to consider if the employer will be inclusive of disabled people. Some employers are meeting their commitments. However, some people with MS also said that, after starting their job, they realised an employer being in the scheme can mean little in reality, as their new employer was not at all supportive, despite claiming to be.

One of the main issues is the scheme is voluntary, and does not have any legal powers of enforcement. Employers are trusted to self-report. This means there is no requirement for there to be strong evidence an employer signed up to the scheme is meeting its commitments. It is possible for an employer to be accredited without actually employing one disabled person. In 2018, less than half of employers said, as a result of joining the scheme, they had recruited one or more individuals with a disability, long-term health condition or mental health condition.¹⁷

The Government should strengthen the Disability Confident employer scheme. This should include introducing mandatory reporting for all employers, and making those at Disability Confident levels 2 and 3 meet minimum thresholds for the percentage of disabled people in their workforce. Over time the

Recommendation

The Government should strengthen the Disability Confident employer scheme:

- Bring in mandatory reporting for all employers
- Make employers at levels 2 and 3 meet minimum thresholds for the percentage of disabled people in their workforce

Government should consider mandatory remedial action for employers who consistently fail to meet minimum thresholds. These changes to the scheme would help people with MS have more confidence employers signed up to the scheme do genuinely live up to their commitments to recruit and retain disabled people, and support them in the workplace.

“The Disability Confident Scheme is good but there is a wariness about the scheme among the MS community. There are different levels of membership and it can be seen as a tick-box exercise for employers.”

Alice's story



Alice was diagnosed with MS aged 24. She left her place of work due to stress and for the next five years worked part-time, whilst also claiming disability benefits.

When Alice felt well enough to work more, she planned to increase her hours gradually, enabling her to get back into full time work at her own pace. However this meant her ESA moved to Universal Credit and it was reduced from £900 a month to £23.

Alice says because of this she was forced to increase her hours more rapidly than first planned, which luckily her employer was able to do. Fortunately, this has been a positive step forward for Alice, even though the pace was much quicker than she originally hoped.

Alice has started to think about increasing her hours further and working full-time. This is in part because her employer has made efforts to support her and talks with her about what adjustments she might

“Everyone’s MS is different, and there’s no blanket solution to help people with MS in the workplace. That’s why it’s so important that employers speak to you and try to understand your specific needs and concerns.”

need. Working full time in an office can be really tiring, but I’m able to work from home a few days a week.

It suits me really well and means that I can get more done.” Alice’s employer also allows her to work flexibly around her regular hospital appointments.

Even though Alice feels well supported at work, she does think that there is a lack of awareness about MS in her workplace. “My symptoms are invisible so it can be hard for people to understand (and remember.) For example, when I was working less, people in my office used to say I was “so lucky” for being able to have days off to do nothing. They didn’t understand it wasn’t a holiday, it was time I needed to enable me to do my job.” Alice says she feels like she has to explain herself a lot and would like to see training available to help workplaces be more inclusive and understand how to support disabled people.

02

Staying in work

Most people begin experiencing MS symptoms between the ages of 20-40, during the peak of their working lives. Many move out of work early, with previous research saying 80% of people with MS retire within 15 years of their diagnosis.¹⁸ For some the decision to stop working is right for them, often because the severity of their MS symptoms has made working impossible. However, others were forced to leave work earlier than they wanted to because they could not get the support they needed from their employer and the Government. For example, 24% of people with MS in England who retired early or left work entirely as a result of their MS said they wanted to stay in work, but their employer did not support them.¹⁹

Often employers fail to help people with MS to stay in work because they lack information and advice on what MS is and how people with this condition can be supported. People with MS themselves lack information on what support they can get, and on their legal rights. The Government does not do enough to make sure employers put in place reasonable adjustments, including not being tough enough on employers who fail to make them.

Some people with MS get government support to help them stay in work, notably from the Access to Work scheme. Sadly, awareness of this scheme is still too low and there are issues with the application, renewal and assessment processes. This means too many

80%

of people with MS retire within 15 years of their diagnosis

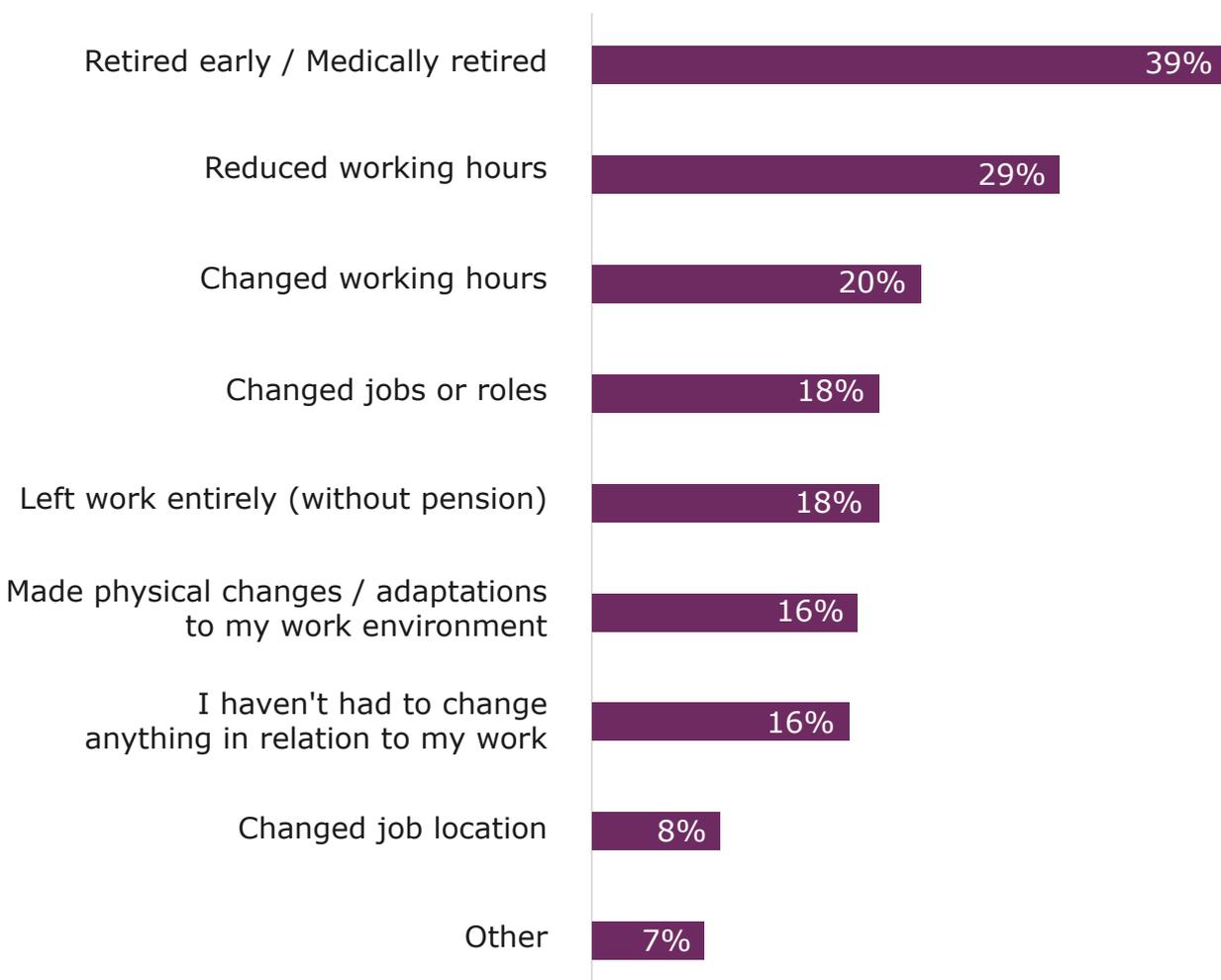
“I will live with my MS longer than I will live without it and I want to know that there will be something put in place for others like me not to fall through the cracks. It’s hard to know where to turn.”

people with MS do not get Access to Work support, which could help them stay in work longer.

An inflexible and inadequate statutory sick pay system means people with MS do not get the support they need while they are on sick leave, sometimes leading to worsening symptoms and an increased chance of them leaving work earlier. And too many employers do not have effective policies in place to support their employees with MS to successfully return to work after sickness absence.

This section looks at the main barriers people with MS said they face to staying in work, and sets out a number of ways the Government and employers should help all people with MS stay in work for as long as is right for them.

Have you done any of the following as a result of your MS?



Information and advice for employers and people with MS

Employers having clear information and advice on MS, and on how people with this condition can be supported, is felt by people with MS to play an important role in their needs being understood and supported at work. Sadly, many people with MS think there is not enough information and advice of this type available for employers, in one easily accessible location. This means some are not getting the support they need to stay in work.

This lack of clear information can cause employers to have misconceptions about MS and feel unable to support them at work. In some cases, employers may be worried about taking on people with MS entirely. Employers need condition-specific information, to help them understand the full impact MS can have on someone at work. And on how they can respond to people with MS disclosing their diagnosis in positive ways. There needs to be more information on how they can support an employee with MS at work and to help them understand many reasonable adjustments are free and easy to make. Employers need positive examples of adjustments being put in place, best practice guides, and advice on their legal obligations around reasonable adjustments.

It is important employees with MS know and understand their legal rights at work, and can find advice and support on other issues they may have in the workplace. Without this, some people with MS are going without support that could help them to stay in work, as they do not know what they can ask for or access. As with the information and advice for

Recommendation

The Government should set up a 'one-stop shop' of information and advice for employers and employees to help them understand how people with MS can be supported at work.

It should include:

- Condition-specific information on MS for employers
- Advice on how people with MS can be supported to stay in work
- Signposting to where additional support can be accessed
- Information on reasonable adjustments, including on the legal duty for employers

employers, much of the content for employees is not available in one easily accessible place.

The Government should set up a 'one-stop shop' to give this information, accessible through a range of channels and in different formats. The 'one-stop shop' should include condition-specific information on MS and advice on how people with MS can be helped to stay in work. This should include signposting to places where support can be accessed, such as Access to Work and sources in the voluntary sector. There also needs to be clear information for employers and employees on reasonable adjustments and employers' legal obligations.

It is welcome the Government has established a new 'advice hub' in collaboration with the Advisory, Conciliation and Arbitration Service (ACAS), giving information on employment rights for disabled people.²⁰ The hub has some useful advice, particularly on reasonable adjustments and legal rights. However, employers and employees cannot get all information they need from the hub to understand how someone with MS can be supported at work, given there is no MS-specific information available. The hub is also only available online, meaning people without internet access cannot access it.

The 'one-stop shop' needs to be much broader in its scope than the newly established hub with clear, in-depth information on MS and advice on what can be done to support people with this condition at work. It should be made available through different channels such as online, by phone and on paper. It needs to be well publicised, properly funded and created in close consultation with employers and employees to make sure the information meets their needs.

While this section of the report talks about support to help people with MS stay in work, the 'one-stop shop' would also be important for helping employers and

“Self-advocacy is key and dependant on how much agency individuals feel they have. You don't want to push it. I have to prioritise what I needed so that I'm more likely to get those things which are vital. My current employer has been amazing, but I only ask for things if I really need them. However, I am confident where others are not.”

employees better understand how people with MS can be supported to move into, and out of, work. For example, it should give advice on how people with MS and employers can have productive conversations during recruitment about the support that can be put in place once the employee starts in their role. It should also advise on how reasonable adjustments can be made to help people with MS successfully leave work when it is right for them, and signpost to out-of-work benefits and support.

“When it comes to adjustments employers are under the belief that it costs a lot of money. My employer hasn’t had to spend a huge amount... The majority of changes have been to my working hours, my working pattern.”

Reasonable adjustments

A reasonable adjustment is a change an employer has to make to remove or reduce a disadvantage related to an employee's disability when doing their job. Many people with MS can manage their condition better and stay in work for as long they want to due to their employers making the reasonable adjustments they need. These include changes to working hours, a chair or stool to sit on and their work station being moved closer to a toilet. Failure to put in place the necessary adjustments someone needs can cause people with MS to struggle with their symptoms at work, and, in some cases, force them to leave work earlier than they wanted to.

There is a legal duty on employers to put in place reasonable adjustments under the Equality Act unless they can demonstrate there is a business reason not to.²¹ Despite this duty, a number of people with MS, across sectors and roles, and including those working flexibly or from home, said their employers did not put in place the reasonable adjustments they asked for. This includes when the Access to Work scheme had recommended, and agreed to fund, the adjustments following an assessment.

Some people with MS said their employers cited 'business reasons' for not putting in place reasonable adjustments, without being given useful information about what these 'business reasons' were. Often employers cite concerns around the cost and difficulty of putting reasonable adjustments in place. However, with support from Access to Work, better information, and discussions with the employee, they are likely to find, in reality, the cost and difficulty of putting in place a reasonable adjustment is low.

People with MS do not think the existing legal duty is effective enough for making sure they get the adjustments they need. Employers do not need to give a written response within a certain period to employees who request an adjustment. And they

Recommendation

The Government should do more to make sure employers make reasonable adjustments for people with MS:

- Take stronger action against employers who fail to put in place reasonable adjustments
- Strengthen the Equality Act duty, by making employers give a written response to employees' requests within two weeks, and give employees a timeframe for when the adjustments will be put in place
- Help people with MS assert their legal rights, by reversing legal aid cuts and reducing delays in cases being heard at employment tribunals

do not have to give an estimated timeframe to their employees for how long it will take to put in place adjustments.

There is little people with MS can do to compel their employers to make reasonable adjustments. Cuts to legal aid in England and Wales mean some people with MS are excluded from being able to challenge their employer, as they cannot access legal advice and representation. These cuts have disproportionately negatively impacted those from more marginalised groups, such as people on lower incomes, who are more likely to need legal aid.²²

There are also significant delays affecting employment tribunals in England, Scotland and Wales, with many people waiting several months for their cases to be heard.²³ These delays mean some employees who are challenging their employer for a failure to make a reasonable adjustment are left with no choice but to leave their jobs in the months before the case is heard. This is because they cannot cope at work for such a long period without the adjustment in place.

The Government needs to make sure employers make the reasonable adjustments disabled people need to help them stay in work. Better information, advice (as outlined above) and better guidance can help employers understand and comply with their obligations. So it is welcome the Government has announced the Health and Safety Executive (HSE) will explore strengthening 'non-statutory guidance' relating to reasonable adjustments.²⁴

However, encouraging employers to do the right thing through guidance only goes so far in making sure employers will make adjustments. The Government also needs to take stronger action against employers who fail to comply with the current requirements. And it should strengthen the legal duty by requiring employers to give a written response to employees'

“With one employer I pushed and pushed myself to keep working without adjustments and made myself more ill.”

“I went through years of physical, mental and emotional turmoil of doing the job, when the only major barrier was a physical one.”

requests within two weeks and to give them a timeframe for when the adjustments will be put in place.

Tighter rules should be brought in to make sure employers put in place adjustments recommended by Access to Work. More support needs to be given to empower disabled people to assert their legal rights and challenge employers who do not make adjustments. This should include taking urgent action to reduce delays in cases being heard at employment tribunals and reversing legal aid cuts. More funding should be given to the HSE to help this body more effectively investigate complaints against employers.

Some people with MS, and their employers, have received support from occupational health (OH) services, including being advised of reasonable adjustments that could be made to support the employee with MS to remain in work. Sadly, those working for small and medium-sized enterprises (SMEs) are more likely to miss out on this support as OH services tend to be attached to larger employers. This means they may not be getting the reasonable adjustments they need. The Government needs to increase the provision of OH services, particularly at smaller employers. All people with MS should be get specialist support from an occupational health professional, regardless of their employer's size or sector.

By making sure employers make reasonable adjustments, the Government would help more people with MS stay in work for longer. These changes would also help people with MS to move into and out of work. For example, people with MS who are looking for work would be more confident potential employers will make the adjustments they need. And more people with MS would get the adjustments they need to successfully transition out of work, such as phased exits.

“It was great to have them [an Occupational Therapist] look at my whole work life and identify things that were having a negative impact and make recommendations for things that needed to change.”

Michelle Ennis (Clinical Lead Occupational Therapist) and The Walton Centre Employment Clinic



“[The Walton Centre’s employment clinic is about] empowering people to have those difficult discussions about work with employers and empowering people’s self-efficacy to challenge”

The Walton Centre is the country’s only NHST Trust dedicated to Neuroscience.

The Occupational Therapists (OT) run The Walton Centre’s Employment Clinic, supporting people with Multiple Sclerosis (MS) to find work, stay in work, and leave work when it’s right for them. The interventions are directed towards “empowering people to have those difficult discussions about work with employers and empowering people’s self-efficacy to challenge”. The OT team encourages patients to explore the barriers they face when it comes to work – physical, cognitive and emotional. The assessment starts by asking routine questions about their job, how long they’ve been there, and what support they have. Together, the patient and the OT undertake a ‘Task Analysis’ going through all the tasks the role requires, and then looking at how easily they can do them or for how long they can do them and what the challenges are. The OT also spends a lot of time talking to the person with MS about what work means to them, and what work gives to them.

“The most important thing is to integrate work into healthcare intervention and not as an afterthought. It needs someone in employment services that understands and is an expert in MS.”

Michelle often sees people who have no idea about what is available to them, or the rights they have at work, for example, reasonable adjustments or flexible working. Unfortunately, she says people often reach the clinic when they are already facing problems at work, but would like to see people being given this information when they are diagnosed. “The most important thing is to integrate work into healthcare intervention and not as an afterthought. It needs someone in employment services that understands and is an expert in MS.” Michelle supports her patients to have discussions with their employers, signposting them to schemes that could help or legal advice, and providing information on the different options people have as they transition out of work.

The Employment Clinic has many success stories. Patients have come to the clinic feeling disheartened and with no option but to leave work, but with targeted support have gone on to “get new jobs, and promotions, but a lot of people with MS are so surprised by this. They think they’re lucky to have the job they have, but they have that job because they’re skilled and qualified. It’s not luck.”

Access to Work

The Government's Access to Work scheme provides valuable support to people with MS, helping them to remain in work for as long as is right for them. The scheme provides practical, mental health and communication support. And many people find it easy to access the scheme and get the help they need.

However, some people with MS had less positive experiences, such as finding the application process hard to navigate and getting poor customer service. There have been reports of lengthy delays in funding and adjustments being put in place, particularly during the COVID-19 pandemic. These delays risk putting employers off taking on people with MS - as they do not have a timely guarantee support will be funded - and people with MS may not be working while they wait for support to be put in place.

Changes should be made to the Access to Work scheme to make sure it better supports people with MS to stay in work. This should include making the application and renewal process more accessible, efficient and flexible and reducing delays in support being provided.

Some people with MS miss out on certain types of support they need, as it falls outside the remit of practical, mental health and communication support. Assessments need to take more of a holistic approach, which should include looking at working hours, practices and addressing employers' concerns around costs and difficulties of putting in place adjustments.

The flexible support offer introduced during the COVID-19 pandemic should also be kept in place permanently. This includes support for people who are home working or hybrid working (a combination of working from different locations, including home).

Recommendation

The Government should improve Access to Work so it supports people with MS to stay in work:

- Make the application and renewal process more accessible, efficient and flexible and reduce delays in support being given
- Make assessments more holistic, such as providing advice for employers around making reasonable adjustments
- Run a publicity campaign to increase awareness of the scheme

There is a lack of awareness about the scheme amongst disabled people and employers. Only 25% of employers know about the scheme and understand the help they can get from it.²⁵ The Government should run a publicity campaign through a range of channels to increase awareness of the scheme amongst people with MS and their employers and to make sure people are getting all the support they can to remain in work.

Sick pay

People with MS may need to take time away from work for reasons related to their MS. This can be for varying lengths of time, depending on the person's circumstances, and can include taking time off when they are experiencing a relapse and to attend medical appointments.

Some people with MS are well supported by their employer and can take the time off they need on full pay. When people with MS can get the financial support they need while they are off work, they can often stay in work longer as they can better manage their symptoms in the long-term.

However, others are not entitled to any levels of occupational sick pay (OSP), and are reliant on statutory sick pay (SSP) while they are off work. A good SSP system should help people with MS stay in work for as long as they wish to. But the current SSP system in the UK is failing to do this.

In 2019, the Government published the Health is Everyone's Business (HIEB) consultation, which set out proposals for reforming the SSP system.²⁶ This included changing SSP rules to help an employee returning from a period of sickness absence to have a flexible, phased return to work and extending protection to those earning less than the Lower Earnings Limit (currently £118 per week).²⁷

Recommendation

The Government should strengthen the statutory sick pay (SSP) system so it can support people with MS to stay in work:

- Take forward the proposals in Health is Everyone's Business (HIEB) for reforming the SSP system
- Extend the proposal for flexible SSP (in HIEB) to people who need a phased exit from work into a period of absence
- Allow people to claim SSP from day one of their absence
- Increase the rate of SSP to the National Living Wage

To make sure the SSP system can support people with MS to stay in work, the Government should take forward the proposals from HIEB and strengthen the system further. The proposal for flexible SSP should be extended to people who need a phased exit from work into a period of absence, allowing people to manage their condition better by tapering work and sick pay.

The waiting time of four days to claim SSP does not work for people with MS. Many people with MS experience occasional short periods of absence, rather than extended periods, due to the fluctuating nature of their condition. Those who are off for fewer than four days are not entitled to claim SSP, and they can sometimes be forced to take these absences as unpaid leave or annual leave, if they are not entitled to any form of OSP. The Government should bring back the changes made to qualifying days introduced during the COVID-19 pandemic, allowing people to claim SSP from day one of their absence.

People with MS who go onto SSP are likely to experience a big drop in income. SSP is only paid at a rate of £96.35 per week, well below the national average weekly salary. This reduction in income disproportionately negatively affects disabled people due to the extra costs they have. For example, people with neurological conditions can face, on average, extra costs of up to £200 per week.²⁸ This loss of income caused by moving onto SSP can lead to significant lifestyle changes for someone with MS. This includes some changes that can lead to worsening health such as being unable to afford taxi fares to attend appointments. It is no surprise some people with MS said they avoided taking time off work and others were forced back to work earlier than they wanted, due to not being able to cover their costs while on SSP. This is not sustainable in the long-term, and could potentially lead to people being off longer. Or having to leave work altogether because of their health.

“After a period of sick leave I asked for a sabbatical, making a business case for it and was granted it. With SSP it feels like when the tap runs out you’re kind of dumped and left to fend for yourself.”

Not only do people with MS think the rate of SSP is too low, around 62% of employers also think the rate is too low and should be increased.²⁹ The rate of SSP should be increased to the rate of National Living Wage. This would help to reduce the large drop in income felt by people who receive SSP under the current system.

The Government proposed to increase employers' compliance with SSP by increasing fines for employers in breach of the duty to pay SSP.³⁰ This proposal is positive and should be taken forward. However, there needs to be caution this approach does not have the unintended effect of putting off employers from employing disabled people in the first place.

As well as strengthening the SSP system, the Government should explore how to increase the number of employers paying OSP. This could include looking at how to make sure there is more parity in OSP rates across employers and sectors.

Return to work policies

Many people with MS do get the structured support they need from their employer to help them to return to work, helping them to manage their symptoms better and stay in work longer. Sadly, there are still too many people with MS who are not supported to have a successful and dignified return by employers who do not have the right return to work policies in place, or who are not following their policies correctly. This can include the employer failing to stay in contact with them when they were off work, leaving them feeling forgotten and not valued.

People said adjustments were not put in place to help them ease back into work, and the advice of health professionals was sometimes ignored by employers. Having an unsuccessful return to work can be distressing for people with MS. It can sometimes lead to their symptoms getting worse and them being forced to move out of work earlier than they would have hoped.

Employers should have policies in place to provide structured support to people with MS to help them to successfully return to work in a way that works for them. This should include employers staying in touch with employees while they are off work and following the recommendations of the employees' health care professionals.

Employers cannot subject disabled employees to disciplinary measures if they are off work as a result of their disability. However, some people with MS are unaware of this duty on employers. This means they may have been discriminated against, without their knowledge, if their employer subjected them to a disciplinary for taking disability-related leave. Evidence also shows a sizeable number of employers do not have policies which differentiate between sick leave and disability-related leave.³¹

Recommendation

Employers should have policies in place to support people with MS to return to work. Policies should state:

- Employees should receive structured support to help them return to the workplace, including employers staying in touch with them while they are off work and following the recommendations of the employees' health care professionals
- A range of options should be made available to help employees ease back into their roles, including reasonable adjustments
- Disability-related leave should be treated differently to sick leave

Policies should state a range of options must be given to help people ease back into their roles. For example, a slow increase in working hours, changes to workload, and reasonable adjustments. And disability-related leave must be treated differently to sick leave. If persistent or long-term absence from work is affecting the ability of a person with MS to do their job, the employer should treat this as a capability issue, not a disciplinary issue.

Employers may need HR expertise or similar support to help them get the right return to work policies in place. This may be particularly relevant for SMEs. The Government should consider providing support to SMEs to help them access this expertise.

Owen's story



Owen has secondary progressive MS, and has been with his current employer since he was first diagnosed in 2017.

He works for NHS Wales as a Support and Business Analyst. Owen knew that one day his MS would affect his work, so decided to disclose his MS to his employer as soon as he was diagnosed. He wanted to be upfront and knew that further down the line not disclosing could cause problems trying to access support.

While there wasn't much understanding of MS within the organisation they took steps to try to understand the impact it could have. Owen's employers have worked with him to develop a chronic illness management plan. This enabled Owen and his line manager to speak about what the impact of Owen's MS might be and what support could be put in place now and in the future, including a personal evacuation plan, and an absence management process. Having open and frank conversations with his employer has helped him get the support he needs and he feels fortunate that he is in a position where he feels comfortable to do this.

“My employer has responded much better than I could have hoped for...they will do everything they can to support me to do my role...people with MS need support to do their role, but that support doesn't have to be drastic, or to reduce hours.”

Owen has received support from Access to Work. At first he was highly concerned applying for Access to Work would be similar to PIP. However the scheme has given him access to all kinds of support including specialist equipment and hardware.

Owen has had to find ways to manage his fatigue, spasticity, limited mobility and brain fog to enable him to carry out his work. As Owen's MS has progressed he is considering asking for a reasonable adjustment to work from home which he is confident will be accepted as he's worked from home throughout the Covid-19 pandemic. Owen is also conscious however, that this shift in workplace may have had a detrimental effect on his symptoms.

Owen says that work “gives me a reason to be” but working as a disabled person isn't easy. He says that “if I wasn't with the employer I'm with now, would I still be working? Would they have been as supportive or would I have had to leave? Surely it's easier for an employer to keep someone on the books they know can do the role than find someone new.”

03

Leaving work

Deciding to leave work is a deeply complicated and personal decision for people with MS, which involves weighing up health needs with financial and emotional worries. Once someone has made that decision, being able to leave work when it works for them, and in a way that suits them, can be incredibly difficult for many people with MS. This is because, too often, they do not receive the support they need from their employer or the Government to leave work successfully and with dignity.

Having an unsuccessful exit from work can be distressing for people with MS, making them feel let down by their employer and knocking their confidence. And sometimes it can make their symptoms get worse. People with MS need structured support from their employer to leave work in a way that is right for them. But employers often do not have in place effective policies setting out how people should be supported to leave work. Many fail to put in place reasonable adjustments for their employees, which would help them to have a phased exit.

As people with MS move out of work, there is a lack of effective signposting and support from employers and the Government to help them navigate the benefits and support they may need and be entitled to. Too many people with MS find the welfare system stressful to navigate, including being poorly treated

“There will be a point where I will have to look at ill health retirement. I’m not even 40 and to be looking at that at this stage is a scary prospect.”

by DWP, getting the wrong levels of support, and being subject to benefit sanctions. Benefit rates are also too low for supporting disabled people, including people with MS, to live independent lives, free from poverty. This all at a time when someone may be struggling with their health, and significant changes in their life.

This section sets out the main barriers people with MS face during their transition out of work, and after they have left work, and sets out how employers and the Government can make sure people with MS are better supported during this process.

Leaving work policies

Some people with MS said they received the structured support they needed from their employer to have a positive exit from work when it was right for them, and in a way they wanted to. Successful exits can allow people with MS to better manage their symptoms and plan ahead to get support in place for once they have retired. However, there are some who did not feel well supported by their employer.

Employers should put in place, and follow, policies to support people with MS to transition out of work when it is right for them. Policies must make sure employers consider all reasonable adjustments that could be made to allow someone to have a phased exit from work. This could include reductions in hours, making working hours more flexible, or adapting the workplace, role or location of work. It is important for policies to set out the structured support to be given to people to help them leave work in a dignified way. This should include careers advice, counselling and support to access out-of-work benefits.

Employers and employees should have ongoing conversations during the exit period to see how it is going and consider what changes may need to be put in place to better support the employee. Meaningful exit interviews should always be held shortly before the person with MS leaves work, allowing them to feedback on what they thought did, and did not, go well during the exit process. This would help employers to understand what they need to do to improve in this area.

“When a person leaves there needs to be a thorough process on the employer’s side – have we been open and honest with them? Have we done all we can?”

Recommendation

Employers should put in place, and follow, policies to support people with MS to have a successful and dignified transition out of work, when it is right for them. Policies should state:

- Employers should consider all reasonable adjustments that could be made to allow someone to have a phased exit from work
- Employers and employees should have ongoing conversations during the exit from work reviewing how it is going, and meaningful exit interviews should always be held
- Employees should be given careers advice, counselling and support to access out-of-work benefits

Signposting to benefits and support

Many people with MS claim out-of-work benefits after leaving work. Some had previous experience of interacting with the welfare system before they left work, including claiming PIP. However, others had to navigate it for the first time in their lives to get the out-of-work benefits they needed.

When leaving work, some people with MS said they felt like they were 'left to their own devices' in working out what support they could get. This was particularly felt by those who had never interacted with the welfare system before.

Not knowing what support they can get makes the process of leaving work even harder for people with MS. And it means some people with MS are missing out on vital support they need after they have left work. This includes support to help manage the changes in their life. Work can be a big part of someone's identity, and leaving can have an impact on someone's mental health.

Too many people with MS said they were not signposted to all the support they could get, either by their employer or by the Government. Many said online advice from the Government was not clear enough, and there was little information on what other support they may be able to get when they made their first claim for a benefit.

Once they have given notice they wish to leave work, a person with MS should be given clear information by their employer on the benefits and support they can get after work. They should be signposted to where they can go for more advice. Employers could consider giving anyone who is leaving work one point of contact, such as an HR staff member, who can help them to understand what support they can get. And help them to put in place out-of-work support

“It’s that period in-between, a massive gap of time from leaving work and then claiming. It’s a tough decision to make – leaving work with the hope that you might have enough.”

Recommendation

Employers and the Government should improve support given to people with MS to help them access benefits and support once they have left work:

- Employers should give employees information on the benefits and support they may get after work, and signposting them to where they can go for more advice
- The Government should give clear and easily accessible advice

in advance of them leaving work. As set out above, the provision of this support should be set out in employers' leaving work policies.

The Government should give clear and easily accessible advice on the benefits and sources of support for disabled people and how to apply for or access them. This should be established within the 'one-stop shop' (outlined above) and be available through a range of channels. All people with MS should be able easily start claims for disability benefits either online, by phone, by post or in person. At the time of, or shortly after, making a claim for a benefit, they should be given clear information on other benefits and support and advice on how to apply. And everyone who starts a claim for a disability benefit should be given the right to get a single point of contact in the DWP. This DWP staff member would help them understand the other benefits and support they may get, and support them to apply for them.

“They should be open... ‘this is what you’re entitled to, what is your living situation’, and that support should be there for you, because when you come from a full-time job and you’re just thrown into this world, it’s like they keep it hidden from you.”

through the 'one-stop shop' (as set out in the 'Staying in work' section of this report) on the benefits and sources of support for people with MS and how to apply for or access them

- The Government should make sure everyone who starts a claim for a disability benefit is given one point of contact in the DWP to help them understand the benefits and support they may be able to get, and support them to apply

Welfare system

After leaving work, many people with MS do not get the support they need from the welfare system. People with MS found the system stressful to navigate, including being poorly treated by staff working for the DWP. Often people do not get the level of support they are entitled to first time round and have to go through the appeals process to get it. Once people are successful in their claim, the current rates are not high enough to allow many people with MS to cover the extra disability-related costs they face.

Once people with MS have left work, they may be able to get employment income replacement benefits such as Employment and Support Allowance (ESA) or Universal Credit (UC). Issues with the Work Capability Assessment (WCA) for ESA lead to far too many people with MS not getting the right level of out-of-work support. This is often due to poor practice by assessors who have no knowledge of their condition and assessment criteria failing to take into account the fluctuating nature and hidden symptoms of MS.³²

After applying for ESA and UC, far too many people with MS are wrongly placed into the work-related activity group (WRAG) and the limited capability for work group (LCW). Many people with MS in these groups do not get the level of financial support they need. Being in these groups also means people need to meet certain job search conditions to get their benefit or they risk getting a 'sanction'. This is where their benefit amount is reduced by the DWP. People can experience anxiety due to sanctions, and there is little evidence they help people find and move into high-quality and secure employment.³³

The WCA criteria should be changed to more effectively consider the fluctuating nature and hidden symptoms of MS, and informal observations should no longer play any role in assessments. Evidence collection processes for assessments also need to

Recommendations

The Government should make sure the welfare system provides adequate and appropriate support to those who cannot work due to their MS:

- Change the Work Capability Assessment (WCA) criteria so it more effectively considers the fluctuating nature and hidden symptoms of MS, and scrapping informal observations
- Make sure staff working for the DWP treat disabled people with empathy, dignity and respect at all times
- Make sure no disabled people are subject to benefit sanctions and conditionality
- Set benefit rates at a level that means disabled people can cover their costs and live independent lives

be improved, and people with MS should only be assessed by someone who has some professional experience of neurological conditions. The DWP should make sure no disabled people are subject to benefit sanctions and conditionality.

Some people with MS said they felt like they were treated like 'liars' and 'frauds' by staff during their assessments.³⁴ This is unacceptable and the Government must make sure staff working for the DWP treat all disabled people with empathy, dignity and respect at all times. People with MS should be believed by assessors and not assumed to be lying about their condition. It should always be accepted people with MS are the experts in their condition and how it affects them. These standards should be strictly enforced and embedded across all DWP services.

Recently published research from the DWP shows benefit rates are inadequate for enabling many disabled people to pay their bills or cover their extra disability-related costs.³⁵ These extra costs can amount to £200 per week, on average, for people with neurological conditions.³⁶ And with a cost of living crisis affecting the UK in 2022, it is even harder for disabled people to get by.³⁷

Many people with MS rely on benefits to support themselves, including those who cannot work due to their disability. This should not condemn them to a life of poverty. Not getting the right level of support means people with MS struggle to live independently and cover their daily costs, let alone the extra costs they face due to their disability.

Benefit rates should be set at a level that means all disabled people, including people with MS, can cover all their costs and live independent lives. These rates should be informed by research on minimum income standards.

“They made me feel like I was scum and I was lieing (sic). They had all my proof and letters from all the NHS staff. I was reduced to tears. I never asked to get this awful disease.”

Amy's story



Amy was diagnosed with Relapsing Remitting MS in March 2016.

Describing herself as headstrong, at first she tried to carry on as usual, but after 18 months Amy had a relapse which left her unable to walk or talk. Amy says following her relapse she was forced to face up to “everything” and be more open about her condition. Amy’s relapse meant that she needed speech therapy, she was in pain and for a while only had use of her thumbs.

At the time Amy had two jobs and said their responses couldn’t have been more different. One employer was really supportive allowing her to return at her own place and putting in place reasonable adjustments, including providing her with an assistant to help her. Her other employer contacted her every few days asking when she would be returning, despite her being signed off by the doctor. After a month Amy was told that her pay was going to be docked by 50%, which left her no choice but to return. “I had to sit at my computer for hours on end, despite being in agony a lot of the time.”

“They made sure to ask if I was ok. It took me a while to build up my confidence, but I’m now at the point where I’m completely open and honest about my condition with them.”

Amy pushed for an occupational health assessment and got one, but her employer didn’t discuss it or implement any of the recommendations. Without an HR department, Amy had few options and says it’s important that people have someone to go to and raise any issues at their workplace. Amy said she became increasingly unhappy with the way she was being treated and felt she had no choice but to leave despite knowing this would lead to a struggle to pay bills, and difficulty finding another similar role.

Her employer was shocked when she handed in her notice. “They had no inkling that I was thinking about leaving, but they took absolutely no steps whatsoever to try to improve things to help me to stay, despite saying they were disappointed I was leaving.”

Amy says that leaving was the best decision for her health, but this was made easier knowing she had another job. Having such a supportive employer in her other job has shown her how things should be and she now trains people to help them understand why diversity and inclusion are so important.

04

Wider barriers to employment

The main focus of this report is on the steps directly related to employment the Government and employers should take to support people with MS find, move into and stay in high-quality work, and move out of their job when it is right for them. However, people with MS face barriers in many other areas of their life, not directly linked to employment, which negatively affect their employment outcomes. As well as following the main employment-related recommendations in this report, it is vital the Government also reduce the barriers to healthcare, social care, housing, transport, and digital access and skills experienced by people with MS. While we cover each of these barriers briefly here, they are also areas of work which the MS Society continues to work on.

Healthcare

Having prompt access to appropriate healthcare services is important for helping people with MS to effectively manage their condition. This includes rehabilitation services supporting people with MS to maintain mobility, and access to psychological support helping them to come to terms with their diagnosis and how their symptoms affect their abilities.

Access to these services can play a crucial role in improving the employment outcomes of people with MS, including helping people to stay in their role for as long as is right for them and to avoid reaching crisis point in the workplace.³⁸ However, too many people could not get appropriate support when they needed it. For example, evidence from August 2020 showed since the COVID-19 lockdown had begun in March 2020, seven in 10 people with MS had not been able to speak to a rehabilitation professional when they needed to.³⁹

Some people with MS said they benefitted from having work-related conversations with healthcare professionals (HCPs), including being given advice on adjustments and their legal rights at work. Getting this support, particularly at the point of diagnosis, can make a positive difference to people with MS being able to stay in work longer.⁴⁰

Sadly, too few people can get work-related support from their HCP. This is despite NICE guidelines saying HCPs should provide information on legal rights, including on employment, to patients at the point of their diagnosis, and employment should be discussed at comprehensive reviews.⁴¹

There are a number of reasons why HCPs do not talk about employment with their patients. This includes struggling with large workloads, and lacking training

Recommendations

The Government should reduce the barriers to healthcare experienced by people with MS, which negatively impact their employment outcomes. This should include:

- Making all people with MS have timely access to appropriate health services, including a full multi-disciplinary team
- Providing healthcare professionals (HCPs) with better guidance for how to have effective work-related conversations with people with MS
- Increasing the number of MS specialist HCPs to a level which would give them time to have meaningful conversations about work with their patients

on employment issues and how to recognise the work-related barriers people with MS face.⁴²

“I think it would be good for people to be told at the time of their diagnosis about the support they can ask for from their employers.”

Social care

The social care system in England is not meeting needs of disabled people. One in three people with MS do not get the support they need with essential day-to-day activities.⁴³ A lack of access to care can affect people’s ability to move into and stay in employment. For example, some people with MS need help getting ready in the morning before work.

Last year, the Government announced plans to improve the social care system in England, however the proposals do not go far enough. The Government needs to increase funding to make sure all disabled people can get the care they need. It should improve pay and conditions across the social care sector, which are a major contributing factor in staff shortages. And there needs to be more training to support the care workforce to provide individualised, person-centred care.

Many family and friends also provide care for people with MS (often called informal carers) and they are missing out on support. This form of care can be vital to people with MS, but often those providing it don’t have the practical, emotional or financial support they need. Many informal carers rely on Carer’s Allowance (a benefit paid to those caring for someone for more than 35 hours a week) however it is paid at a very low rate, and there is a lack of support, with carers being given little respite.

Recommendations

The Government should reduce the barriers to social care experienced by people with MS, which negatively impact their employment outcomes. This should include:

- Improving pay and conditions across the social care sector
- Giving the care workforce more training to support them to provide individualised, person-centred care
- Increasing the rate of Carer’s Allowance
- Introducing 10 days of paid leave for informal carers

Housing

Across the UK, there is a severe shortage of accessible homes for disabled people, including people with MS. Disabled people are more likely to live in social housing, yet this sector is under particular pressure, with long waiting lists.. In the private rented sector, far too many landlords are not willing to put in place adaptations or other support.⁴⁴

Barriers to accessible housing play a significant role in disabled people struggling to access employment. For example, disabled people whose accessible housing needs are not met are four times more likely to be unemployed or not seeking work than those whose needs are met, or those who are disabled but do not need accessible housing.⁴⁵

Recommendations

The Government should reduce the barriers to housing experienced by people with MS, which negatively impact their employment outcomes. This should include:

- Building far more accessible, adaptable and affordable homes for disabled people
- Improving the installation of home adaptations
- Making sure people with MS are more effectively matched to suitable homes in the social housing sector

Transport

People with MS who receive the higher rate mobility component of PIP can swap some of their benefits for access to an adapted vehicle through the Motability scheme.⁴⁶ This can help people with MS to live independently, including being able to get to and from work more easily. Sadly, many people with MS who need support from the scheme are denied it. This can be despite not being able to carry out daily activities without the vehicle. Inadequate PIP assessment criteria, in particular the 20-metre rule for assessing mobility, are one of the main reasons too many people with MS do not get the higher level of mobility support and miss out on access to the scheme.

Many people with MS said they lack access to accessible public transport. This affects those living everywhere, although is particularly acute in less urban areas. One of the main barriers is bus stops being too far from people's homes.⁴⁷ For those without access to their own vehicle, not being able to access public transport can mean a loss of independence and struggling to access employment.

Recommendations

The Government should reduce the barriers to transport experienced by people with MS, which negatively impact their employment outcomes. This should include:

- Scrapping the 20-metre rule for assessing mobility in PIP assessments
- Reviewing the criteria, scope and rules of the Motability scheme
- The Motability scheme should be made available to disabled people who are on standard mobility PIP or low mobility DLA and to disabled people not claiming PIP
- Making sure all disabled people have easy and affordable access to accessible public transport

Digital access and skills

Across the UK, in all age groups, disabled people are far more likely to lack digital access than non-disabled people. The digital divide refers to the gap between those who benefit from digital access and skills, and those who do not. The divide is particularly stark in the 35 to 44 year old age group, a time when people are at the peak of their working lives. Disabled adults in this age group are 24 times more likely to have never used the internet than non-disabled adults in the same age group.⁴⁸

People with MS without digital access are excluded from even finding or applying for many jobs in the first place. Given a high number of roles are now advertised exclusively online. Some people with MS may also lack the digital skills needed to find and apply for jobs online.

The Government often takes a 'digital by default' to providing services, with many moved from offline to digital channels. This means some disabled people without digital access and skills struggle to access government support to help them at find and move into work, and struggle to access out-of-work benefits. By ensuring that they provide non-digital channels at the same level of quality and access to the Government will help people with MS move into and stay in employment, and access the welfare system.

Recommendations

The Government should reduce the digital-related barriers experienced by people with MS, which negatively impact their employment outcomes. This should include:

- Improving digital access and skills amongst disabled people, including providing funding for organisations such as the Good Things Foundation,⁴⁹ working to reduce the digital divide
- Making sure people can access all government services via non-digital channels at the same level of quality and accessibility as via digital channels

Conclusion

Like everyone else, people with MS want to be able to find suitable and high-quality work. They want to be in jobs which match their skills, interests and experience, and which fit around their other commitments. And they want to be able to stay in work for as long as is right for them. People with MS want to be able to progress in their careers, and not feel lucky to simply have a job in the first place. And when they can no longer work due to their condition, they want to know they will be able to live independently, and with dignity.

These aspirations are modest. But for too many people with MS, they are out of reach. This is because they do not get the support they need from the Government or employers. It should not be this way. The Government and employers should listen closely to the experiences of people with MS in this report, and follow its recommendations for action. It's what people with MS deserve.

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We're the MS Society.

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

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