

the work foundation



## **Ready to Work:**

# **Meeting the employment and career aspirations of people with multiple sclerosis**

*Stephen Bevan, Ksenia Zheltoukhova, Robin McGee and Laura Blazey*





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## Foreword by Dame Carol Black

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*Both the ageing of the UK workforce and the increase in chronic diseases are focusing the minds of healthcare professionals and policy-makers on the growing need to support people with long term and chronic conditions who want to work. Although there is still much to be done, we are moving slowly towards a more widespread understanding that - for many people - work can be part of their rehabilitation and return to health and well-being. Work is such an important aspect of life because it helps people retain their self-confidence and a sense of being a productive member of society.*

*As I travel around the country, I see more employers understanding that retaining and supporting people through differing health conditions is both a more sensitive and a more cost-effective way of handling absence from work, rather than absorbing the substantial costs of redundancy and recruitment. At last, the relentless focus on incapacity is being replaced by a perspective that values what people can do. I hope that the introduction of the Fit Note, which concentrates on capacity, is reinforcing this more enlightened perspective.*

*The Work Foundation has been a prominent influence on this debate both in the UK and internationally, and its research on the health of the workforce has done much to keep the needs of people with long-term conditions in the public eye. This new report brings together evidence and insights from a variety of sources to highlight some of the key issues impacting people with multiple sclerosis (MS) during their working life. It aims to increase awareness, stimulate debate and encourage innovation amongst policy-makers and practitioners to improve the lives of individuals with MS. Like so many chronic conditions with a fluctuating course, MS can be unpredictable, with periods of remission and stability as well as periods which are debilitating. It requires GPs and employers to be imaginative and thoughtful in the way they support job retention or return to work.*

*I very much welcome this report. I hope that its messages about the importance of work to people with chronic conditions will be heard by employers and healthcare professionals. I hope it will be read widely and the Calls to Action considered carefully by those who can make the most difference to people with MS who want to work.*

A handwritten signature in black ink that reads "Carol Black".

Dame Carol Black  
National Director for Work and Health

## Executive summary

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This report highlights the problems faced by people of working age in the UK who have multiple sclerosis (MS) and what more can be done to support them to live full and meaningful working lives. **Work opens doors for people and can provide income, a sense of purpose, dignity and social connectivity. The authors argue that, with more co-ordinated action, the majority of people with MS who want to work can be kept in fulfilling employment.**

## Main findings

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MS is a chronic neurological condition that is often diagnosed during prime working years and is one of the most common causes of disability amongst young adults. It is a progressive condition with no current cure that varies in each individual case. As one MS specialist said, some people may be *“relatively well, and then, have this diagnosis thrust upon them”*.

MS affects up to 100,000 people in the UK and 2.5 million worldwide. Due to its unpredictable and fluctuating nature, MS can impact an individual's quality of life as well as their ability to work. Premature loss of employment by people with MS and their informal carers incurs significant costs to the UK labour market and economy:

- On average, 37 per cent of people with mild MS are employed, although many have to change or quit their jobs due to fluctuating functional capability.
- More than 75 per cent of people with MS report that the condition has impacted their employment and career opportunities.
- Up to 80 per cent of people with MS stop working within 15 years of the onset of the condition.
- At the same time 30% of individuals with a significant level of disability remain in employment.
- Up to 44 per cent of people with MS retire early due to their condition – a higher percentage than the European average (35 per cent).
- As a result of reduced availability of social services, a considerable burden of the costs associated with MS falls on those with the condition and their carers.

- Professional careers of 57 per cent of relatives are adversely affected by MS of a family member.
- People with MS lose an average of 18 working years, assuming a retirement age of 60. If one worker with MS draws Employment Support Allowance (ESA) for 18 years the total cost (at 2011 prices) will be £61,000. If 20,000 people are on ESA benefits for 18 years the **cost to the welfare system is over £1.2 billion**. This takes no account of the income tax which these workers would be paying.
- The annual costs of MS may vary from £12,000 for those with low disability scores to £60,000 for those with severe disability stage. One estimate suggests that **MS costs UK society about £2.3 billion** per year.

Many people with MS want to work; with the right support they could continue to live full and productive lives for much longer. Yet during periods of economic downturn and job losses people with long term or chronic health problems, such as MS, may feel especially vulnerable. Our research shows that many employers lack knowledge about the condition and may not always understand that the needs of employees with MS can and should be accommodated at the workplace.

MS is a 'hidden disease' and the extent of its impact is not visible to others. A number of symptoms, including depression and anxiety, limitations in mobility, reduced dexterity, slurred speech, urinary and faecal frequency and urgency, and cognitive impairment causing memory and concentration difficulties, can limit the ability of people with MS to work. Over 80 percent of individuals are affected by fatigue, which can significantly impact on their ability to perform all routine activities of their daily lives.

Poor awareness of the fluctuating nature of MS and many of its unseen symptoms in the job context among some employers, GPs and policymakers may delay access to disability benefits, NHS care and workplace interventions for people with MS. Delayed access to care and treatment has implications for health outcomes. However, a range of interventions is available to support individuals' functional capacity to remain independent and to stay at work.

## What interventions are needed?

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Staying in or increasingly returning to work is being considered as an important clinical outcome for individuals with MS. No cure is currently available, yet there are interventions that can significantly reduce the impact the condition has on the lives of those with the condition and their ability to remain in employment. Depending on the individual's circumstances, the most effective intervention, or combination of interventions, may vary. However, the report identifies those which are likely to have greatest impact, highlighting that access to these interventions should be improved:

- In the health care environment, a wide variety of interventions (ranging from traditional pharmacologic medicines to **fatigue management** courses and **cognitive behavioural therapy**) are available to target the symptoms or slow down the progress of the condition, and access to these needs to be improved. Innovative research and further developments in the interventions already available may identify more effective courses of treatment.
- Within the work environment reasonable adjustments and schemes like 'Access to Work' may prevent a premature decision to leave a job during a difficult time. **Flexible working hours**, scheduled **work breaks** with a place to rest, improved awareness of MS amongst colleagues and increased **support** from employers and colleagues may all assist individuals with MS to remain in work. At the same time, one stakeholder described this scheme as the '*government's best kept secret*' because awareness about the programme is lacking.
- **MS specialist nurses** are the first point of contact for 91 per cent of people with MS regarding the support and coordination on various interventions, schemes and resources available to them. The help provided by MS specialist health professionals is a cost-effective way to manage the condition, as MS nurses play an important role in coordinating care and empowering people with MS, for example, in managing disclosure discussions, which may be particularly helpful in the employment setting.

Early diagnosis and intervention are often central to improved job retention or a successful return to work. While disclosure of MS may help individuals to accommodate the symptoms within their work environment, many are concerned with the risks of revealing the condition to the employer. It is essential that the **positive psychological impact of staying in work** is taken into account when planning and delivering both clinical and workplace interventions for people with MS.

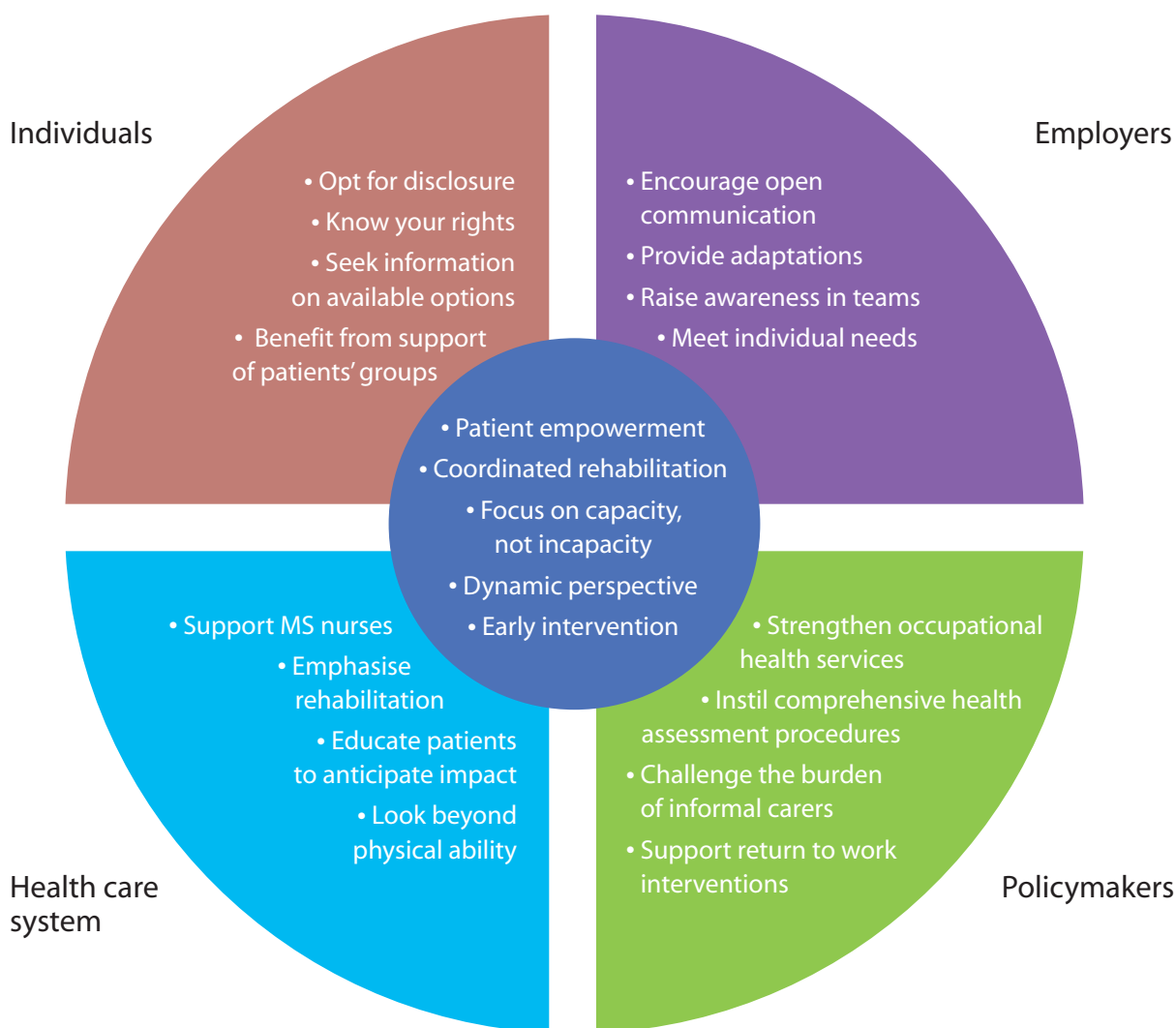
## Call to action

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The significant impact of MS on those with the condition, families, employers and wider society is not well recognised. Participation in **work** for people with long-term conditions is now a specific goal in the new NHS Outcomes Framework. Interventions now focus on the **capacity** of individuals with MS, rather than their incapacity. This should help to focus minds on what can be done to **maximise labour market participation** among people with MS.

A range of stakeholders must work together to reduce and prevent the impact of long-term health conditions on the ability of individuals to remain at work. One example of best practice in establishing cooperation of individuals, employers, healthcare providers

and policy-makers in reducing the cost of ill health to the UK economy is the 'Charter for Work' developed by the Arthritis and Musculoskeletal Alliance. The Charter calls for actions required of each group of stakeholders to support people with musculoskeletal disorders to stay in work. A similar charter could be developed for MS, which could help empower the stakeholders to begin or continue discussions about needs at work by taking a comprehensive and holistic approach to MS.



Four important stakeholders contribute significantly to providing the early, holistic, and well coordinated care that is needed to improve outcomes for people with MS: individuals, employers, health professionals and policy makers. The report calls upon each of them to take action.

**Individuals** need to be **assertive self-advocates** of their rights and take an active role in managing their condition. In addition, they need to:

- **Think proactively** about their careers and the adjustments that they need to continue working.
- **Tell their employers about their condition** in order to get timely access to support at work. Many people are reluctant to disclose information about their MS – and this has to be based on the individual's choice, but early disclosure is essential if effective and optimal support is to be organised.
- Take an active role in managing their condition and highlight to their employers and co-workers how **changes to working time and working practices** could maximise their productivity at work.

Individuals need to discuss all of their options with their families, their health professionals and their employers before making any decision to leave the workforce. They also need to seek out support when making important career decisions.

**By learning more about MS**, employers will become more aware of the impact of its fluctuating nature. Employers need to:

- Enable managers to provide a flexible **working environment** (eg accommodating simple changes to working time arrangements) to help people with MS to stay in or return to work.
- Aim to preserve **job quality**, avoid excessive or damaging job demands and take heed of **ergonomic good practice** (vocational rehabilitation, carefully organised and tailored to the individual, can make a real difference to return to work, productivity, morale and sustainability of performance).
- Involve **occupational health professionals** as early as possible to assist disclosure and access to appropriate intervention for individuals with MS.
- Work together with GPs to **support phased return to work** according to the Fit Note.

Employers need to do more to retain the talent of their existing staff living with MS. This means nothing more than making sure that they follow current best employment practice: looking at flexible working hours, making reasonable adjustments in the workplace and striving to keep employees in meaningful roles with support from individuals and health professionals.

**Health professionals** need to consider employment as an important outcome for individuals with MS and in particular, they need to:

- Coordinate care through **multi-disciplinary teams** of occupational health workers, specialist nurses and physiotherapists to help individuals with MS maintain or return to employment.
- Recognise that **people with MS are often workers too**. Begin **discussions about work** and the careers of those with MS soon after diagnosis.
- Use the **Fit Note** to indicate which aspects of work, and with what support, people with MS can still perform.

Health Professionals need to think about an individual's work as a key part of their wellbeing, and make sure they can access the most up-to-date advice and support to help them stay in, or return to, the workforce as long as they are able and willing to work.

**Policy makers** should support effective interventions that improve health outcomes for individuals with MS and help them remain in work. In particular, they need to:

- Maintain the **'Access to Work' scheme** and encourage discussion about job retention.
- Recognise the impact changes to the welfare system may have on individuals with MS and rethink the **assessment process with regard to the fluctuating nature** of the condition.
- Recognise the important role of MS specialist health professionals, such as **specialist MS nurses and physiotherapists**, in coordinating care and supporting individuals with navigating available interventions, receiving **timely diagnosis** and **accessing appropriate treatment**.

- Recognise and promote the role of **occupational health professionals** in helping employers – large and small – to accommodate the needs of workers with MS and to encourage creation of **quality jobs** to support job retention and return to work among people with MS.

Policymakers should continue current programmes like Access to Work to make sure that such schemes are better adapted to the fluctuating nature of MS. Most of all, they need to deliver on current policy direction to support individuals to stay in the workforce, coordinating the cooperation of individuals, their employers and health professionals.

## About the report

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Qualitative interviews were conducted with a number of stakeholders and experts who have in-depth knowledge of MS, including patients, clinicians and nurses, academics, and representatives of patient groups and charities such as those listed below.

**More information on living with MS is available at:**

MS Society: <http://www.mssociety.org.uk/>

MS Trust: <http://www.mstrust.org.uk/>

Multiple Sclerosis Resource Centre: <http://www.msrmc.co.uk/>

**A full copy of the report is available as a free download at:**

[www.theworkfoundation.com](http://www.theworkfoundation.com)

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