

# Ready to Work?

## Meeting the Employment and Career Aspirations of People with Multiple Sclerosis

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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 health care 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 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 health care 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". The signature is written in a cursive, flowing style.

Dame Carol Black  
**National Director for Work and Health**

## 1. 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.**

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### Main findings

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, however, 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 per cent 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, limit the ability of people with MS to work. Over 80 per cent 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.

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### What interventions are needed?

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 MS 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.

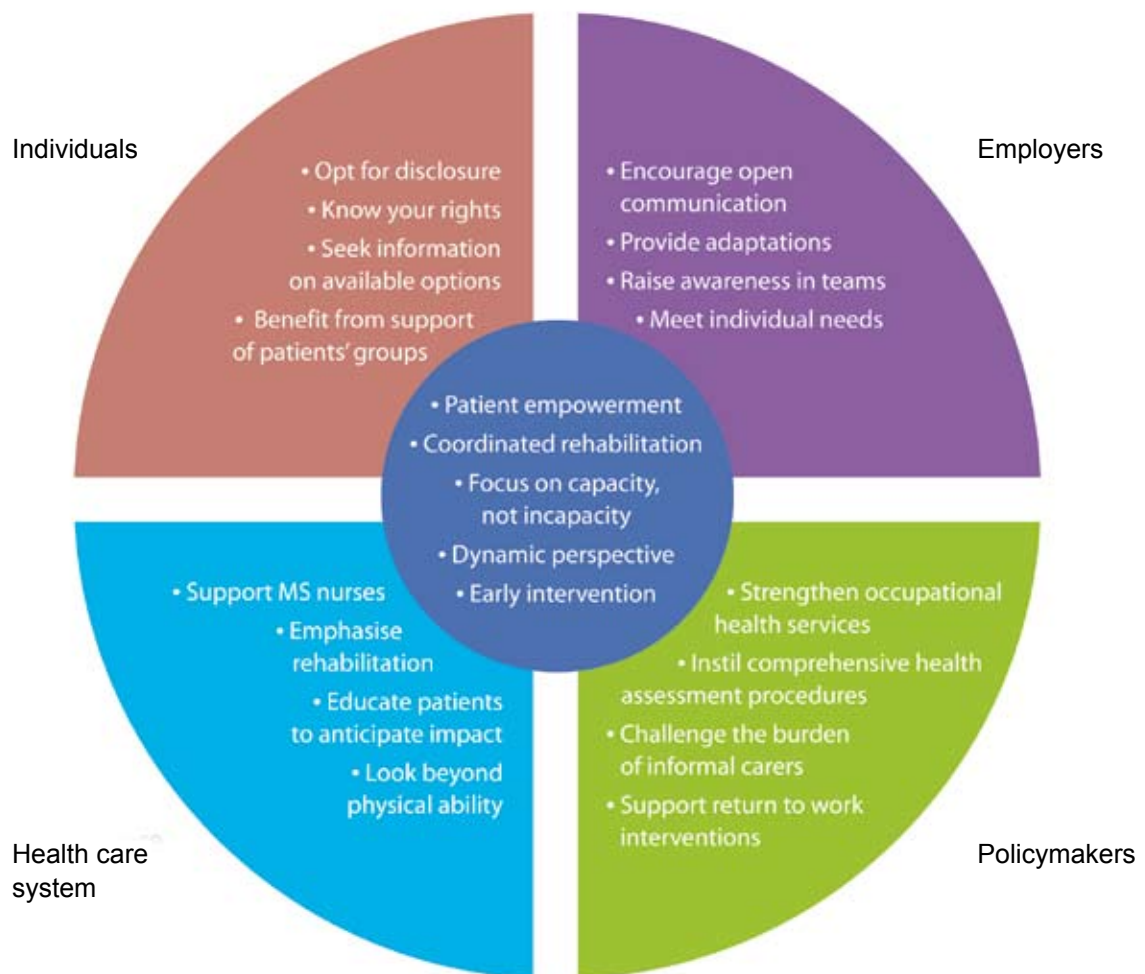
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### Calls to action

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, health care 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:

- Co-ordinate 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.

## 2. Introduction

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While the UK economy is starting to crawl out of the recession, the employment situation remains tenuous with cuts to the public sector scheduled over the next few years. Already, people with chronic health problems have a harder time gaining and maintaining employment (Schuring, Burdorf, Kunst and Mackenbach, 2007), which impacts not only on employment outcomes but health outcomes as well. High levels of job insecurity are associated with worse mental health outcomes, general health outcomes (Ferrie, Shipley, Stansfeld and Marmot, 2002) and the development of long standing illnesses or disability (Bartley, Sacker and Clarke, 2004). Individuals with chronic health conditions, such as multiple sclerosis (MS), may also feel especially vulnerable during difficult economic periods. Uncertainty in working conditions leads to increased levels of stress. Employees with chronic health problems already experience additional stress related to the management of their condition. The stress related to dealing with and managing their condition may 'spillover' into the job, and vice versa, where the job stress may impact their management of the condition (Gignac, Sutton and Badley, 2006).

Work, specifically good work, is good for health (Coats and Lehki, 2008; Marmot et al., 2010; Bartley, Sacker and Clarke, 2004). For most, good working conditions can positively impact health by providing economic security, offering a sense of social contact and status and contributing to overall wellbeing. 'Good work' has been characterised (Coats and Lehki, 2008) as work where there is:

- Autonomy, control and task discretion;
- Balance between effort and reward;
- Employment security;
- A match between skills and work demands;
- Procedural justice;
- Strong workplace relationships (social capital);
- Work that is not characterised by monotony and repetition.

For those with chronic health conditions, a good working environment may be a requirement in order to reduce the ill affects that work can have on individuals. Some research suggests that when an individual has a chronic health condition the additional presence of continual work stress increases sickness absence and disability (Dewa, Lin, Kooehoorn and Goldner, 2007).

However, employees who require assistance from their employer to address changes to the workplace to accommodate their chronic health condition or disability may not ask for assistance due to fear of discrimination and potential job loss. Evidence suggests that

individuals with previous long-term absence or frequent absence are more likely to experience involuntary termination (Koopmans, Roelen and Groothoff, 2008; Virtanen, Kivimaki, Vahtera, Elovainio, Sund, Virtanen, et al., 2006).

Individuals with MS comprise a particular group whose health condition impacts their employment prospects considerably. Around 2.5 million people worldwide have MS (WHO, 2007). MS is a chronic neurological condition that is often diagnosed during prime working years and is one of the most common causes of disability among young adults. It is an unpredictable condition that varies by each individual case. Over time MS may result in a number of difficulties that can impact an individual's quality of life as well as ability to work.

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**2.1**  
**UK policy**  
**changes**

The effort to make cuts across a number of government departments and reduce the amount of people receiving welfare benefits has a number of implications for individuals with long-term or chronic health conditions. These changes will have implications for delivery of care through the NHS, access to interventions and availability of financial benefits. It is clear that the landscape is changing quite rapidly.

The 2010 White Paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010) calls for an NHS with 'a relentless focus on delivering the outcomes that matter most to people'. As patients are often the best experts on their own health, the NHS Outcomes Framework builds on this by including a specific framework section which focuses on enhancing quality of life for people with long-term conditions (LTCs). 'Functional ability' is noted as a desired improvement area, with data on the employment of people with LTCs being collected as an indicator for this outcome. In 2011, the government published its personalised care planning strategy, which aims to improve support for people with LTCs and to help them to have better social and working lives. The strategy recognises that in addition to medical needs, other issues affect the health and well-being of a person with a LTC. It therefore urges patients and health care professionals to work together to consider the impact of the LTC on their quality of life, not just restricted to health but considering broader issues including education and work, and to help the patient to achieve the outcome that they want for themselves.

*Welfare to Work* reforms are intended, at least in part, to focus the welfare system on the 'capacity' of individuals rather than their 'incapacity'. To introduce measures designed to support people in finding sustainable work and to ensure that disabled people have the same opportunities as non-disabled people to succeed in life and fully participate in society. To deliver these outcomes, both the *Welfare Reform Bill 2011* and *The Work Programme* prospectus

highlight the need to treat people as individuals and to understand their capabilities and tailor support to their individual needs. This is important when considering those with MS. Work Programme delivery partners, advisers and employers will need to be educated on the nature and consequences of the fluctuating symptoms that certain LTCs produce and to facilitate action or working plans which account for and accommodate variable stages of disease. New proposals for a Universal Credit appear to offer people with LTCs an opportunity to return to work on a phased or partial basis with 'tapered' benefits which do not penalise work. If this opportunity is delivered then it offers hope to many people with MS who may face significant financial hardship if they come off benefits to return to work.

Yet these initiatives are being debated against a background of high unemployment, especially among the young. Clayton and Brinkley (2011) in *Welfare to What?* point out that little discussion in the welfare reform debate has focused on the job opportunities available in the current economic climate, nor on the quality of these jobs. Part of the difficulty in reducing the number of people on benefits in the current climate is that the economy may not be strong enough to absorb all those found to be 'fit for work'. Removing benefits without creating good quality jobs and without providing effective assistance in finding those jobs risks leaving many in a precarious position of no safety net and no work income.

What is also frequently missing from the discussion is a recognition of the importance of retaining people in work. The focus of much of the benefits reform has centred on returning people back to work after a period out of the labour market. However, for individuals with MS, discussions about remaining in work and adjusting the demands of work may be particularly relevant. Most individuals diagnosed with MS have an employment history, and many are working at the time of diagnosis (Rumrill, 2009). However, even just a few years after diagnosis many have changed their employment conditions or stopped work altogether. While a number of factors contribute to stopping work – including the work environment and work stress, MS-related symptoms and lifestyle choices – more can be done to enable individuals with MS to remain in work.

On the other hand, tightened eligibility criteria for seeking disability allowance may deny some individuals of necessary support due to rigidity of disability assessment through Personal Independence Payment, requiring a health assessment test, and the system of Universal Credit, which may compromise carer premium.<sup>1</sup> Although the new system will consider the degree of impact of health on daily activities and mobility, binary evaluation of the condition – limiting

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<sup>1</sup> See Disability Alliance (2011). Welfare Reform Bill: Tackling or generating disability poverty? Retrieved 17 March 2011 from <http://www.disabilityalliance.org/welfarereformbill.htm>

or severe – together with strict time frame of the assessment may be too crude to consider individual variation in health-related changes in quality of life, in particular with regards to a condition with an unpredictable pattern of progress.

The changes occurring in the NHS will also impact individuals with MS. Already gaps in access to MS care are evident when the UK is compared internationally (Department of Health, 2010). Timely access to care and appropriate interventions may have implications for health which can impact the ability to work.

Phased return to work is needed to support the ability of individuals with MS to remain in employment. The changing conversation from incapacity to capacity with the implementation of the 'Fit Note' provides support for considering work earlier on in the provision of care. At the same time, the Access to Work scheme can help make adjustments in the work place to compensate for variability of performance.

During this time of considerable change in the policy and employment landscape, the needs of people with MS – and those with other similar conditions – can not be pushed to the periphery. Already, individuals with MS have a difficult time living with an unpredictable and fluctuating condition, and more can be done to help maintain stability and continuity in other aspects of life, including employment.

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### **2.2** **Purpose of the report**

A number of organisations and stakeholders have highlighted the impact that MS can have on individuals – particularly during their working life. This report brings together the insights from a variety of sources to highlight some of the key issues impacting individuals during their working life years. With the evidence and recommendations from these sources, this report seeks to increase awareness and stimulate debate, policy and practice to improve the lives of individuals with MS.

With the aim of understanding the impact MS has on working life years, we sought to explore the following three broad questions:

1. What is the impact of multiple sclerosis on working life years?
2. What interventions are available that can reduce the impact of multiple sclerosis on working life years?
3. What can be done to better support individuals with multiple sclerosis during working life years?

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**2.3**  
**A**  
**multi-method**  
**approach**

In order to address the research questions above we employed a multi-methods approach, including the following:

- Desk-based review of the literature;
- Qualitative interviews with stakeholders, experts, and individuals who have MS;
- Secondary data analysis.

**Desk-based review of the literature:**

A desk-based review was carried out to:

- Explore the impact of multiple sclerosis on working life years;
- Identify interventions available that aim to reduce the impact of multiple sclerosis on working life years.

Academic and grey literature was included in this review. The articles were found by using PubMed, Google, Google Scholar, and Web of Science. The key words used in the search included: multiple sclerosis, multiple sclerosis with quality of life, costs, productivity, work, employment, welfare, and interventions.

**Qualitative interviews with relevant stakeholders**

Qualitative interviews were conducted with a variety of stakeholders and experts who have knowledge about MS. We spoke with stakeholders from a wide-range of backgrounds including academia, patient advocacy and health services. Quotes from the interviews are used to illustrate the findings from the desk-based literature review. Additionally, we interviewed individuals who have been diagnosed with MS to better understand their experiences. The questions centred on their health, work and interventions. The information gathered from the interviews is presented throughout the report.

**Secondary data analysis**

A dataset of 194 individuals diagnosed with MS was analysed (Karampampa et al., 2011). The data were collected via a web based questionnaire distributed by UK MS clinicians in 2010. The data are presented in Section 3 of the report. In particular, we compared individuals who were employed versus those who retired due to MS.

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**2.4**  
**Structure**  
**of the report**

- Section 3 describes the impact of MS and presents the data from the secondary data analysis.
- Section 4 assesses the interventions available to reduce the burden of MS.
- Section 5 suggests what the UK can do to support work and careers among people with MS by providing conclusions and recommendations.

### 3. What is the impact of multiple sclerosis?

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Multiple sclerosis (MS) is a chronic disease that impairs functioning of the central nervous system. It affects 85,000 (DWP, 2009) to 100,000 (MS Society, 2010) people in the UK. The condition is already more prevalent in the UK than in other parts of the world and the incidence appears to be increasing. MS is an inflammatory disease which causes damage (demyelination and scarring) to nerve axons in the brain and spinal cord. A variety of neurological symptoms associated with MS result from a weakening ability of the cells to conduct nerve signals. MS can cause disability progressively over time, including difficulty with mobility and upper limb function, bladder, bowel, and sexual dysfunction, speech and swallowing, vision and cognition. Treatment reduces the symptoms, but currently there is no cure to stop the disease.

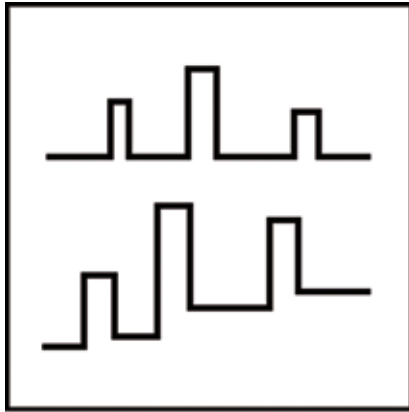
Even with advances in medicine it remains difficult to diagnose MS with certainty (Fox, Bensa, Bray and Zajicek, 2004). Several MS subtypes are defined by the progression of the disease (WHO, 2007). Figure 3.1 on the next page illustrates the patterns of progression.

- The majority of patients (80 per cent) are diagnosed with **relapsing-remitting MS**, which is characterised by periodic disease exacerbations. Exacerbations arise when a sudden onset or increase in symptoms occurs. The symptoms recede fully or partially over the course of a few weeks or months. As time progresses, the relapses may become more severe and recovery may be less complete.
- As the disease progresses patients may receive another diagnosis of **secondary progressive MS**, which is similar to the second most common course of MS, primary progressive course. About 50 per cent of people with relapsing-remitting MS develop secondary progressive MS. Symptoms continue to worsen gradually without distinct remission periods.
- Patients diagnosed with the **primary progressive** course of MS experience a steady worsening of symptoms without preceding exacerbations. About 10 per cent to 15 per cent of patients experience gradual progress of disability from the onset of the disease.
- **Benign MS** is diagnosed retrospectively when accumulated disability from relapsing-remitting MS is mild or non-existent after a long period.

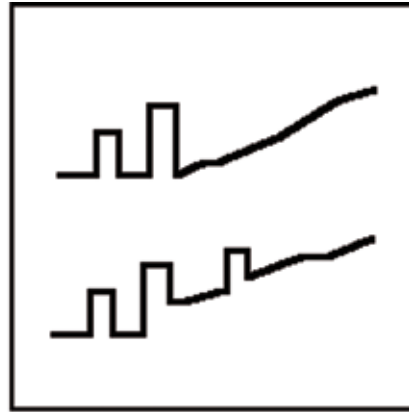
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**3.1 Prevalence and incidence of MS** Often diagnosed between the ages of 20 and 40 (Rumrill, 2009), the prevalence rate of MS in Europe is highest for the 35 to 64 years age group (Pugliatti, Rosati, Carton, Riise, Drulovic, Vecsei et al., 2006). The prevalence of MS is twice as great for women than for men, and MS diagnoses for women are increasing (Pugliatti et al., 2006). Incidence rates of MS in the UK by sex and clinical course are illustrated in the charts on page 20 (Figure 3.2). Across all age-groups, the incidence of relapse-remitting MS per 100,000 person years is 6.6 for women and 2.6 for men, and the incidence of primary progressive MS per 100,000 person years is 0.5 for

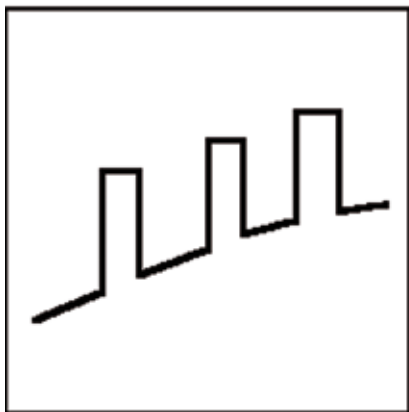
Figure 3.1: Progression of MS by type



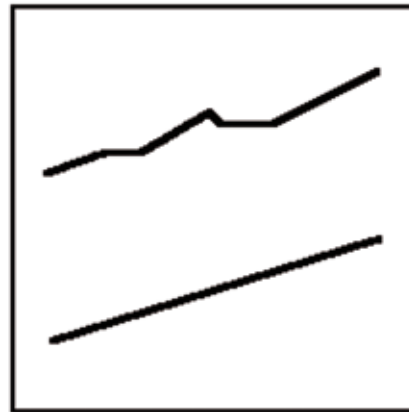
(a) Relapsing-remitting



(b) Secondary progressive



(c) Progressive relapsing



(d) Primary progressive

Source: Lublin and Reingold (1996)

women and 0.5 for men (Alonso, Jick, Olek and Hernán, 2007). As this indicates, the gender gap is smaller for primary progressive, and many more women than men experience relapsing-remitting MS.<sup>2</sup> Figure 3.2 illustrates that the peak time for diagnosis in the UK is 30 to 35 years for relapsing-remitting and about 10 years later for primary progressive (Alonso, Jick, Olek and Hernán, 2007). The majority of respondents in the sample for our secondary data analysis were female (78.9 per cent) and had relapse-remitting MS (72.2 per cent).<sup>3</sup> The average age of diagnosis was about 35, but symptoms started around age 30. As this suggests, MS often

<sup>2</sup> Stakeholder interview

<sup>3</sup> See Appendix 2 for more details

impacts individuals during their most economically productive middle years (Richards, Sampson, Beard and Tappenden, 2002). One of the experts interviewed for this report highlighted low awareness of that impact on patients' working lives:

*'People get MS at relatively early age and their work is most certainly affected. It could be change in jobs, not being able to work at all. Looking at vocational outcomes is very key, and it is surprising that it hasn't been looked at. There should be interventions available to enable someone to stay at work earlier.'*

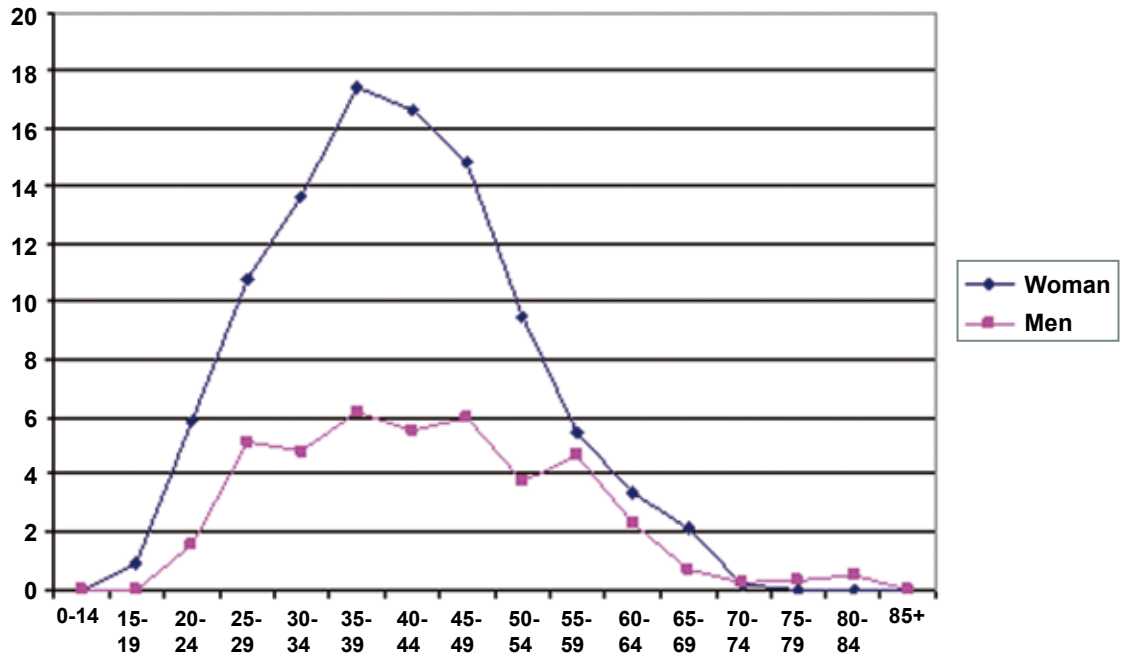
Data presenting prevalence and incidence differences across the UK are limited. Furthermore, comparing prevalence is often difficult due to different classification systems, criteria and sample populations (Ford, Gerry, Johnson, and Williams, 2002; Fox, Bensa, Bray and Zajicek, 2004). A few studies have presented prevalence and/or incidence rates for specific areas. For England and Wales the average prevalence rate is about 110 patients per 100,000 population (Richards, Sampson, Beard and Tappenden, 2002).

In a review of the literature, Pugliatti et al. (2006) report that Scotland and Northern Ireland have the highest prevalence rates. The reported differences in the prevalence between the North and South of England led to the hypothesis of the existence of a latitudinal gradient in the prevalence of MS in the UK (Sutherland, 1956; Swingler and Compston, 1986). Yet growing evidence suggests a 'step-change' in the relative incidence of MS between England and Scotland, as opposed to a gradual increase with increasing latitude (Forbes, Wison and Swingler, 1999). For example, one study based in Devon reports some of the highest prevalence rates at about 117 per 100,000 (Fox, Bensa, Bray and Zajicek, 2004) and in Leeds, the prevalence of MS was about 109 per 100,000 (Ford, Gerry, Johnson and Williams, 2002). These reports support the view that variation in the prevalence of MS within the UK is attributable to differing genetic susceptibility (Pugliatti et al., 2006; Rothwell and Charlton, 1998; Fox, Bensa, Bray and Zajicek, 2004; Ford, Gerry, Johnson and Williams, 2002). Close genetic composition and ethnicity between the Scottish and northern Irish populations may account for the similar risk of MS in each of these populations (Forbes, Wison and Swingler, 1999). Genetic factors are believed to interact in a complex manner with environmental risk factors to determine MS risk (Handel, Handunnetthi, Giovannoni, Ebers and Ramagopalan, 2010; Ebers, 2008).

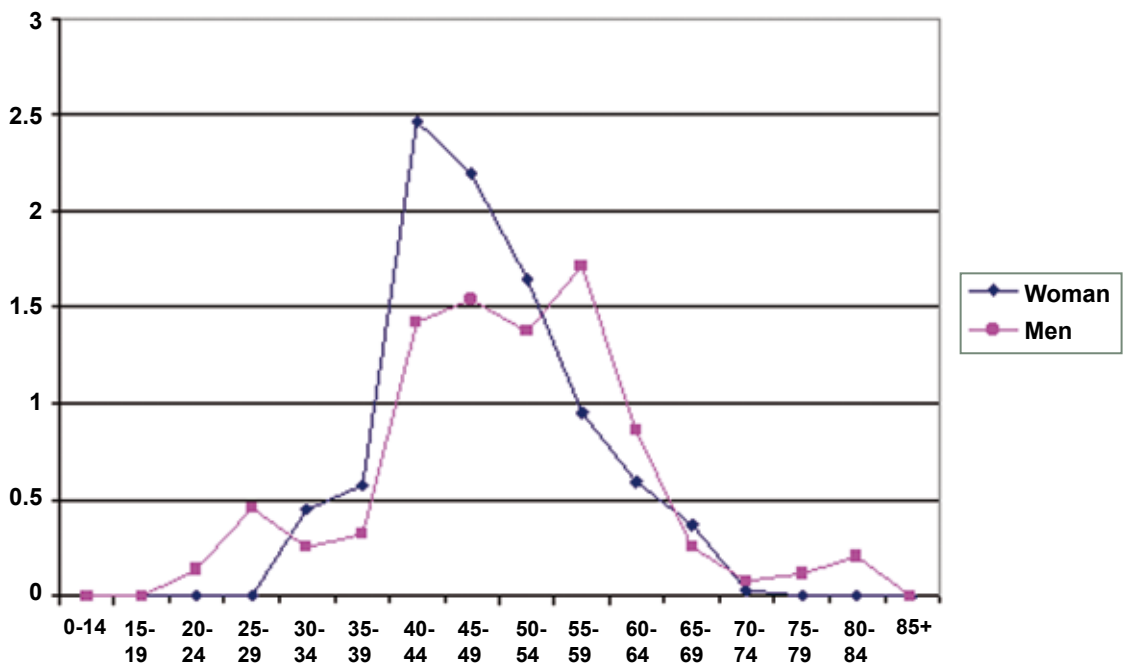
## What is the impact of multiple sclerosis?

**Figure 3.2: Incidence of MS in the UK**

Incidence rates of relapse-remitting MS by sex, 1993-2000 (per 100,000 person years)



Incidence rates of primary progressive MS by sex, 1993-2000 (per 100,000 person years)



Source: Alonso, Jick, Olek and Hernán (2007)

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### 3.2 MS symptoms and their impact

MS affects individuals very differently. On average individuals live with MS for about 30 years (Richards, Sampson, Beard and Tappenden, 2002). It can be unpredictable in its course, and the fluctuating nature of MS can be particularly difficult.<sup>4</sup> Researchers even acknowledge that the existing evidence from longitudinal studies do not answer the questions about the progression of limitations to disability (Stuifbergen, Brown and Phillips, 2009). One stakeholder explained that *'we see people who have been relatively well and then have this diagnosis thrust upon them.'* With a diagnosis of MS, three levels of uncertainty exist.<sup>5</sup>

1. Day-to-day variability in symptoms;
2. Month-to-years variability in terms of relapses and residual disability;
3. Long-term variability in how disability will accumulate.

In the UK, the majority of individuals with MS have moderate disability levels compared with other European countries; however, more people with MS in the UK have higher levels of disability (Pugliatti et al., 2006). A number of symptoms are common, and some of the most frequently experienced symptoms include the following (MS Society, 2010; Richards, Sampson, Beard and Tappenden, 2002):

- Fatigue;
- Pain;
- Visual impairment;
- Numbness;
- Bladder or bowel problems (frequency and incontinence);
- Sensory symptoms (disturbances in touch, for example);
- Weakness;
- Loss of balance;
- Loss of mobility;
- Spasticity;
- Depression;
- Cognitive problems.

Living with the unpredictability associated with MS and the symptoms can impact health-related quality of life considerably. Individuals with MS consistently report lower health-related quality of life compared with other conditions (Jones, Pohar, Warren, Turpin and Warren, 2008; Warren, Turpin, Pohar, Jones and Warren, 2009). A more aggressive disease course is associated with

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<sup>4</sup> Stakeholder interviews

<sup>5</sup> Stakeholder interview

## What is the impact of multiple sclerosis?

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lower levels of health-related quality of life (Benito-Léon, Morales, Rivera-Navarro and Mitchell, 2003). Comorbidity can further worsen health-related quality of life. For example, urinary incontinence and/or depression contributed to reduced levels of health-related quality of life (Warren et al., 2009; Benito-Léon, Morales, Rivera-Navarro and Mitchell, 2003). Other factors frequently related to worse health-related quality of life include: cognitive impairment, fatigue and coping style (Benito-Léon, Morales, Rivera-Navarro and Mitchell, 2003). One of the patients commented on the declining capacity to perform daily activities:

*'As time has gone by the impact on my day-to-day life is increasing...I don't go out as much as I use to. I don't work full-time. I do realistically struggle to go into work. I don't do much exercise. I used to be someone who always prepared a meal every evening, but I don't do that any more. I some times have a cleaner to come in to help clean...Life is more about getting me through each day.'*

Similarly, the unpredictable course of the disease with a varied timing and length of relapses may greatly affect work outcomes. The symptoms associated with the condition that affect patients' ability to be at work include the following (British Society of Rehabilitation Medicine (BSRM), 2010; Julian, Vella, Vollmer, Hadjinichael and Mohr, 2008; Simmons, Tribe and McDonald, 2010):

- Fatigue, anxiety and depression significantly affect work patterns and ability to concentrate;
- Pain and heat intolerance;
- Limitations in mobility place restrictions on physical access to work environment;
- Reduced dexterity complicates handwriting, working on a keyboard, performing manual tasks;
- Slurred speech (dysarthria) impacts communication, use of phone and presentation skills;
- Urinary and faecal frequency and urgency with fear of incontinence presents emotional challenges;
- Visual impairment affects reading;
- Cognitive impairment causing memory and concentration difficulties.

Like many with chronic health problems, depression frequently occurs among individuals with MS (Marrie, Horwitz, Cutter, Tyry, Campagnolo and Vollmer, 2009). The MS Trust (2010) suggests that about 50 per cent of people with MS will experience an episode of depression.

The prevalence of depressive disorders among MS patients is two to three times that of the general population (Kraft, Johnson, Yorkston, Amtmann, Bamer, Bombardier et al., 2008). As in the general population, women with MS have been found to have major depression at a higher rate compared to men with MS (Patten, Metz and Reimer, 2000). The high rates of depression among the MS population may be caused by a variety of factors, including the unpredictable course and uncertainty of the disease (MS Trust, 2010). It is likely that a good proportion of MS patients have depressive symptoms that are unrecognised and untreated (McGuigan and Hutchinson, 2006; Sollom and Kneebone, 2007). This is of particular concern because depression affects psychosocial functioning and adherence to treatment (Zwibel, 2009).

Patients with MS frequently have increased levels of stress and anxiety as well. For individuals with MS, anxiety (Chwastiak and Ehde, 2007) and stress may reduce quality of life, treatment adherence and functional status (Mohr and Cox, 2000; Chwastiak and Ehde, 2007). In addition to dealing with the daily stresses of normal life, individuals diagnosed with MS also have to manage their disease and deal with unpredictable exacerbations of symptoms (Malcomson, Lowe-Strong and Dunwoody, 2008).<sup>6</sup>

The relationship between stress and experiences of a relapse is debateable. Some research indicates that stress increases the likelihood of a relapse, whereas other research does not find a relationship. Anecdotally, many MS patients identify stress as a potential contributing factor.<sup>7</sup> However, evidence from good prospective, longitudinal research studies is lacking, and recall bias may skew the anecdotal reports.<sup>8</sup>

While more data and information are needed to better understand the impact MS has on cognitive functioning,<sup>9</sup> some estimates suggest that between 43 per cent and 70 per cent of individuals with MS have cognitive impairment (Chiaravalloti and DeLuca, 2008). Cognitive impairment may play an important role in functional capability, which includes ability to work and participate in social activities (Chiaravalloti and DeLuca, 2008). Aspects of cognitive functioning that might be affected include the following (Chiaravalloti and DeLuca, 2008; Prakash, Snook, Lewis, Motl and Kramer, 2008):

- Attention;
- Executive functioning;
- Information processing efficiency;

<sup>6</sup> Also reiterated in a stakeholder interview

<sup>7</sup> Stakeholder interview

<sup>8</sup> Stakeholder interview

<sup>9</sup> Stakeholder interviews

## What is the impact of multiple sclerosis?

- Memory and learning;
- Motor functioning;
- Mood and psychological status;
- Processing speed.

Prakash et al. (2008) identified motor functioning and mood status as the cognitive impairments most frequently reported for individuals with relapsing-remitting MS. Some of these impairments may occur early on in the disease stage or may progress with the duration of the diagnosis; additionally fatigue and depression may influence cognitive function (Chiaravalloti and DeLuca, 2008). The role of cognitive functioning is highlighted by the findings of Honarmand, Akbar, Kou and Feinstein (2011) who established the scores on the Multiple Sclerosis Functional Composite – a composite measure of both physical and cognitive functioning – to be the most robust predictor of employment status, exceeding the predictive value of scores on a measure of general disability (the Expanded Disability Status Scale), and individual and global measures of cognitive decline.<sup>10</sup>

Approximately 80 per cent of MS patients experience restrictions in daily activities, which is primarily due to fatigue (Wynia, Middel, van Dijk, de Keyser and Reijneveld, 2008). Fatigue was consistently mentioned in the stakeholder interviews as a key symptom impacting individuals with MS and their working life. In estimating the impact of chronic fatigue syndrome on daily activities, Reynolds, Vernon, Bouchery and Reeves (2004) suggest a 37 per cent decline in household productivity and a 54 per cent reduction in labour force productivity.

Fatigue may make balancing work and life responsibilities difficult. For example, after working all day, some may have little energy for family and/or social life, and this may factor into decisions to leave work earlier (Malcomson, Lowe-Strong and Dunwoody, 2008). At the same time, experts suggest that accepted procedures of clinical assessment are not fit to discount for fluctuations in individual's performance:

*'Because the way the assessment looks at pure functional ability, there is no way to take fatigue into account and its impact on individual's ability to do this one discreet thing. And the effect over the entire day or over the entire working week is not recognised. MS is unique in so many ways, because it's not the kind of pain that is caused by activity.'*

The table below presents the data from the secondary data analysis about which comorbidities impacted the sample. The most frequently reported problem was cognitive problems.

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<sup>10</sup> Appendix 3 explains these measures in more detail

**Table 3.1: Percentage of patients reporting comorbidities**

Comorbidities	%	N
Cognitive problems	51.5%	100
Insomnia	44.8%	87
Depression	38.1%	74
Urinary infection/incontinence	37.6%	73
Hypertension	13.9%	27
Arthritis	8.2%	16
Osteoporosis	2.6%	5

Source: Karampampa et al., 2011

The quote below highlights the additional symptom of fatigue that individuals with MS frequently experience, and how fatigue in particular might impact life and decisions about work. One patient admitted that due to limited physical capacity managing work and family life is always a trade-off:

*‘It is quite hard to get the balance right. I mean I would say at the moment, I don’t have a good work-life balance. But I would not want to give up my job. But I think if, maybe, I could drop say from 5 days to 4 days, it would perhaps make me better outside work to do other things. You know kind of like the best of both worlds, if I could manage to cut my hours down a bit. But I am not sure how practical that is to be honest.’*

Patient interview

**3.3  
Impact on  
caregivers**

MS does not only impact the person diagnosed with it, but also family and friends who may provide informal care. Caregivers play an important role in supporting individuals with MS. The fine balance between providing care and assistance, but also enabling the individuals with MS to continue living and functioning to the best of their ability can be hard to find.<sup>11</sup> One stakeholder described the experience of one family ‘molly-coddling’ the patient to the point that she was not doing enough on her own and fatigue was really starting to become an issue. MS may also strain relationships, because family members may feel a need to take on additional responsibilities (Halper, 2007). Caregiving partners may feel uncertainty about the future, financial difficulties, social disruption and isolation (Halper, 2007). MS is ‘not just about the person with MS,’<sup>12</sup> and the quote below highlights how relationships may change as a result of MS.

<sup>11</sup> Stakeholder interview

<sup>12</sup> Stakeholder interview

## What is the impact of multiple sclerosis?

*'With my husband things have had to change quite dramatically. In that because my fatigue sometimes becomes a problem. I will go to work and I will put in 100 per cent at work but then I come home and that's it. I am finished, and I can't really do much more. Traditionally it's always me who kind of did the cooking, the shopping, the cleaning, and really he has taken over a large part of that. He does most of it, because physically I just can't do it. And it makes me feel quite guilty because I think he works full-time too. He has a lot on his plate. It adds to the burden on him.'*

Patient interview

The table below presents the data from the secondary data analysis about the use of informal caregiving.

**Table 3.2: Percentage of patients reporting needing a caregiver**

Caregiving	%	N
Required assistance during past three months	62.9%	122
From Spouse	47.9%	93
Spouse working	87.1%	81
From Family member	39.7%	77
Family member working	60.0%	45
From Friend	14.9%	29
Friend working	82.1%	23

Source: Karampampa et al., 2011

As these data suggest the majority of individuals with MS require some type of assistance. Frequently a spouse or family member – many of whom are working – will provide this assistance, and as mentioned above, this could impact on their quality of life and working life.

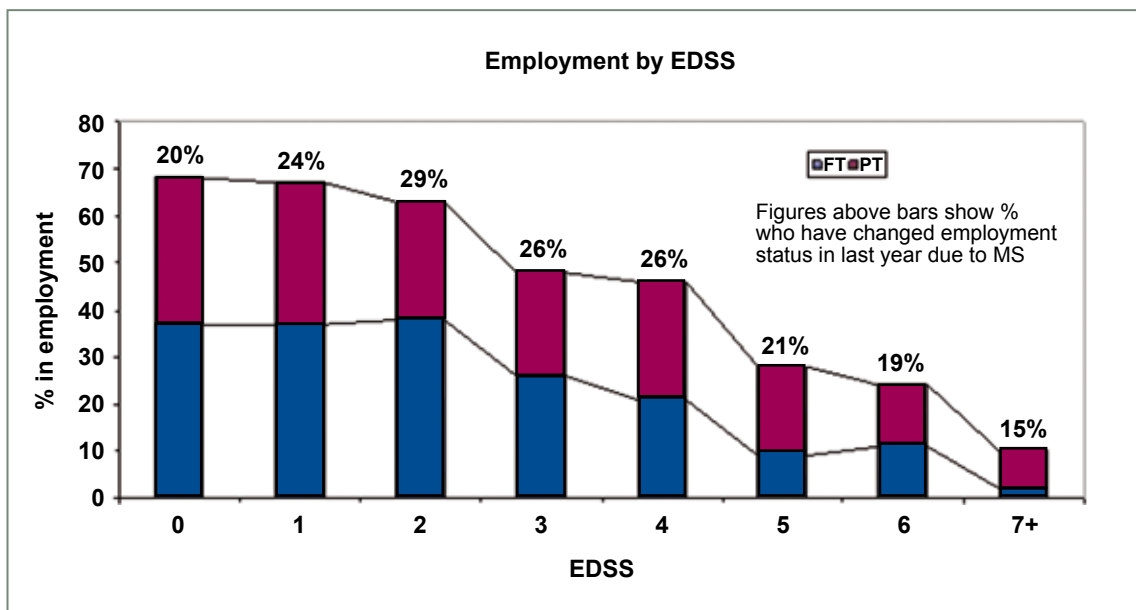
*'I think if family are taking on caring roles or increased responsibility that could in turn affect their work role, so you may have not only the person with MS needing to give up work earlier – that may well happen with the carer.'*

Patient interview

**3.4 MS and working life years**

MS has a significant effect on people’s ability to participate fully in the labour market; evidence suggests that many with MS *‘give up work quite soon.’*<sup>13</sup> Unemployment rates increase steadily with longer duration of MS (O’Connor, Cano, Torrenta, Thompson and Playford, 2005). Around 15 years after the onset of MS between 60 per cent and 80 per cent of patients would have lost their jobs (Zwibel, 2009). On average, 37 per cent of individuals with mild MS are employed, but the percentage drops to 4 per cent for those with severe MS (Naci, Fleurence, Birt and Duhig, 2010). Figure 3.3 below explains that not only many MS patients lose their jobs to progressing disability, but also a large proportion of them have to make adjustments to their work hours due to the condition.

**Figure 3.3: MS patients in full-time and part-time employment, by degree of disability (based on the results of survey of 1295 MS patients in the UK)**



Source: M. Boggild (personal communication, February 2011)

**Note:** EDSS refers to Expanded Disability Status Scale (see Appendix 3).

Additionally, more than 75 per cent of people with MS report that it has impacted their employment – including reducing promotions and increasing early retirement (Green, Todd and Pevalin, 2007). Around 44 per cent of MS patients in the UK retire early because of the condition, compared to 35 per cent across Europe (Kobelt, Berg, Lindgren, Fredrikson and Jonsson, 2006a). With a mean retirement age of 42 (Kobelt, Berg, Lindgren, Kerrigan and

<sup>13</sup> Stakeholder interview

## What is the impact of multiple sclerosis?

Nixon, 2006b) this represents an average loss of 18 working years if we conservatively assume a retirement age of 60. Proposed reasons for the difference in early retirement could be a result of differences in general workforce participation and welfare systems (Kobelt et al., 2006a).<sup>14</sup> An Italian study recognises the importance of sustaining employment after an MS diagnosis and concludes that neurologists encourage newly diagnosed patients to maintain their usual activity (Patti, Pozzilli, Montanari, Pappalardo, Piazza, Levi et al., 2007). On the other hand, one of the experts explains that in the UK work has not yet become a priority among health care professionals:

*'Health professionals have been encouraging patients to step out of the workplace – work is a lot to cope with, because managing MS might be enough. So it might be a thing that got lost along the way.'*

The data about employment outcomes from the secondary data analysis are presented below. The majority of the sample was still working, but 23.2 per cent had retired due to MS. Additionally, of those still working, 37.8 per cent took sick leave in the past three months and 27.0 per cent reduced their salary due to MS.

**Table 3.3: Employment outcomes of MS patients**

Employment status	%	N
Employed	52.1%	101
Self-employed	5.2%	10
Home maker	9.3%	18
Retired due to age	1.0%	2
Retired due to MS	23.2%	45
Student	3.1%	6
Unemployed	6.2%	12
<b>Work Impacts (of those employed or self employed)</b>		
Taken sick leave during past three months	37.8%	42
Reduced salary due to MS	27.0%	30

Source: Karampampa et al., 2011

<sup>14</sup> It is not clear whether the analysis was adjusted for prevalence of MS

Some comparisons between the employed, including self-employed, and retired due to MS are presented below. Individuals who are retired due to MS are older and have higher levels of disability (an EDSS<sup>15</sup> score of 5 or more). Additionally, those who have retired due to MS are more likely to report depression (53 per cent) compared with those still working (30 per cent) and are more likely to report urinary incontinence (53 per cent) compared with those still working (30 per cent).<sup>16</sup>

**Table 3.4: Comparisons by employment status**

	Employed or self-employed	Retired due to MS
Number	111	45
<b>Average age*</b>	41.6	48.6
t(154) = 5.03, p < .001		
<b>Gender</b>		
Female	74%	84%
Male	26%	16%
<b>Disability**</b>		
EDSS less than or equal to 4	70%	27%
EDSS more than or equal to 5	30%	73%
$\chi^2(1, n=156)=24.94, p<0.001$		
<b>Depression**</b>		
No	70%	47%
Yes	30%	53%
$\chi^2(1, n=156)=7.69, p=0.006$		
<b>Urinary tract infection/incontinence**</b>		
No	71%	47%
Yes	29%	53%
$\chi^2(1, n=156)=8.36, p=0.004$		
<b>Cognitive problems</b>		
No	52%	36%
Yes	48%	64%

*Source: Karampampa et al., 2011*

\*Independent samples t-test: statistically significant difference

\*\*Pearson chi-square test; statistically significant difference

<sup>15</sup> Appendix 3 explains the EDSS measurement

<sup>16</sup> The data are cross-sectional. Therefore, the data do not indicate a causal relationship between retiring due to MS and health outcomes

## What is the impact of multiple sclerosis?

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A number of studies have examined which aspects of MS influence people's ability or inability to continue working. One of the factors identified is the course of the disease. Unsurprisingly higher employment rates are found among benign MS patients compared with non-benign groups (83 per cent compared to 35 per cent) (Glad, Nyland, Aarseth, Riise and Myhr, 2010). However, amongst those experiencing a non-benign form of MS, variations in ability to work can still be seen with a non-remittent course negatively influencing people's ability to work (Grønning, Hannisdal and Mellgren, 1990; Glad et al., 2010; Honarmand, Akbar, Kou, and Feinstein, 2011). The longer the course of the illness and the greater the degree of disability experienced by the individual have also been identified as risk factors for unemployment in MS (Honarmand, Akbar, Kou, and Feinstein, 2011; O'Connor et al., 2005). As mentioned earlier, unemployment rates range from between 60 per cent and 80 per cent around 15 years after the onset of MS (Zwibel, 2009). Individuals with MS have a 'below average' household income compared to those without MS even though many have higher education levels and social class (Green, Todd and Pevalin, 2007). With that said, research from Denmark suggests that if individuals with MS remain in work, they maintain a similar income as the general population (Pfleger, Flachs and Koch-Henriksen, 2010a).

Many of factors relating to the ability to remain in work are disease related. A study by O'Connor et al. (2005) identified fatigue (28 per cent), and difficulties with handwriting (26 per cent), balance and walking difficulties (45 per cent) as all having a significant impact on more than a quarter of respondents' ability to work. Similarly, Simmons, Tribe and McDonald (2010) found that for those individuals who left work as a result of their MS, the most common reasons given were related to MS symptoms, particularly: fatigue, problems with legs, feet, arms or hands, difficulty with memory, concentration or thinking, balance or dizziness, and heat sensitivity.

The impact of MS-related symptoms on individuals' ability to work is also highlighted by the finding that significant worsening of symptoms in the last six months were predictive of employment loss when changes in employment over time in MS were examined (Julian et al., 2008). A key aspect of these findings is that it is not simply the physical symptoms that affect the person's ability to work, but a combination of both physical and cognitive functioning. One stakeholder explained that it is difficult to understand when an MS patient will *'look the same but not feel or function in the same.'* This can be particularly difficult for employers to understand.

With symptomatic factors playing a strong role in the ability to remain in work, as well as to perform certain kinds of jobs, Simmons, Tribe and McDonald (2010) conclude that more effective symptom management in the workplace is likely to be an important factor in

maintaining employment. Stakeholders' interviews confirm the role of employers in supporting MS patients:

*'Even when someone wants to stay at work, decrease in cognitive function and fatigue have a real impact on why they decide to stop working. Some employers are supporting them and they can find options for them, but some employers aren't. If it's a manual job, it is more difficult to continue because of fatigue and mobility, and employers have to think of the safety factor.'*

The employment environment can also play a role in employment outcomes for individuals with MS. The type of work carried out appears to influence whether a person with MS is able to stay in work. While Simmons, Tribe and McDonald (2010) found no clear pattern to suggest an association between leaving employment due to MS and occupation type, other findings have indicated that individuals who undertake physical work should be considered at higher risk for early unemployment due to MS (Grønning, Hannisdal and Mellgren, 1990; Pflieger, Flachs and Koch-Henriksen, 2010b; Glad et al., 2010; Pompeii, Moon and McCrory, 2005). While the evidence reviewed above suggests symptom related issues more strongly influence the ability to stay in work than factors relating to the workplace, this highlights that workplace issues should not be ignored. Specific issues that have been identified are difficulties in travelling to and from work, and access while at work (eg wheelchair access) (O'Connor et al., 2005). Furthermore, research conducted by the MS Society highlights particular challenges for individuals with MS in that symptoms may not always be visible to employers or colleagues, and there is a perceived lack of knowledge about the symptoms associated with MS, particularly their fluctuating nature, and a lack of understanding about the impact of these symptoms (Staley and Hanley, 2006).

Research examining job satisfaction and turnover intentions (ie plans to voluntarily leave one's job) amongst individuals with MS may also be helpful in considering what the precursors are to individuals leaving employment. Roessler, Fitzgerald and Rumrill (2004) find that person-job fit, in addition to adequacy of income, was predictive of job satisfaction in employed people with MS and argue that acknowledgement of a poor job match may reflect perceived early signs of inability to perform the job and to meet personal needs through work. Poorly recognised mismatch between job demands, work patterns and changing individual capacity contributes to reduced employment among people with MS (BSRM, 2010). Stakeholders emphasise that employers can think proactively about accommodating MS patients' needs for flexibility at the workplace:

## What is the impact of multiple sclerosis?

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*'Looking at how they plan their day at work, when they have their meetings, and whether it is easier to concentrate in the morning. Thinking what employers can do about that.'*

Additional, external factors influencing participation of people with MS in the labour market include poor adjustment of the employment structures to the needs of patients. This includes physical obstacles, such as open plan offices or inaccessible toilet, inflexible work patterns and lack of employer/colleagues' support (Johnson, Klasner, Amtmann, Kuehn, and Yorkston, 2004). Pack, Turner, Roessler and Robertson (2007) examined the issue from the perspective of turnover intentions amongst employed adults with MS and showed that symptom severity, perceived stress levels and coping ability, job satisfaction, and employer support were all significant predictors of turnover intention. Pack, Turner, Roessler and Robertson (2007) argue that focusing rehabilitation on each of these areas may enable people with MS to retain employment. Again, creative workplace design may resolve many issues that challenge productivity of individuals with MS:

*'Trying to let them do other things at the workplace. But also looking at the work environment. Can they have an office downstairs? A disabled toilet? Facilities to access into building? It might be the environment that is affecting how they perform their role.'*

Expert interview

A further perspective that should be considered is the extent to which individuals with MS are able to re-enter the labour market. Much of the focus of welfare reform is the provision of support for people to find employment which is appropriate to their functional capacity. With a fluctuating condition such as MS it might be assumed that re-entering the labour market after having left it might be an especially difficult challenge. Julian et al. (2008) examined this issue in their study looking at changes in employment across time and found evidence to suggest that employment status in MS should be considered a dynamic process, with 5 per cent of those not working at the first assessment entering into employment by the second time point. Those with higher levels of educational attainment and who were younger were more likely to continue working, as well as those with reductions in symptoms relating to mobility, hand function and cognitive function. The findings relating to the demographic variables of age and educational attainment mirror the relationship found elsewhere showing age and educational attainment as correlates of unemployment in MS (Grønning, Hannisdal and Mellgren, 1990; Pflieger, Flachs and Koch-Henriksen, 2010b). Patients feared the risk of the new employer being not understanding of the impact of their condition:

*'If it is not feasible for me to work part-time where I am, the difficulty is that it's not really feasible for me to go somewhere else and work part-time. Any new employer wouldn't know my worth. [They] would look at that and say no, she has got some illness, we don't want her. That is the reality of life... I am with a company that is a really good company and I do feel that they value me. I am trying to come up with a solution...[and] picking the right moment to tell them.'*

A particular challenge in moving into employment for individuals with MS is the unpredictability of their symptoms, the need to have a realistic understanding of their capacity for work, and to be able to anticipate feeling unwell in the future even if they feel well at the current time (Staley and Hanley, 2006). Flexibility in the workplace in terms of being able to adapt working patterns to fit with periods when individuals are feeling well was identified as a key component of employer support in overcoming some of these issues (Staley and Hanley, 2006). However, it has also been identified that there are a high proportion of individuals who do not receive any support to remain in employment, both for individuals looking to return to work and those who are currently in work (O'Connor et al., 2005). This highlights the need to address some of the issues identified here that influence whether people are able to participate fully in the labour market.

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### 3.5 Costs of MS

MS is one of the most costly neurological diseases, due to its early onset, long duration and significant effects on work and daily activities (Battaglia, Zagami and Messmer, 2000). Management of relapses, progressing disability and comorbidities linked to MS may present a significant financial burden for the patients, the health care system and the economy. In a review of 29 cost-of-illness studies, Naci, Fleurence, Birt and Duhig (2010) identify the following types of costs:

- **Direct medical costs:** hospital stay, inpatient and outpatient care, tests and imaging, pharmaceuticals, transport, social assistance, physiotherapy sessions;
- **Direct non-medical costs:** adaptive devices (eg wheelchair), domestic help, retraining, informal care, personal expenses;
- **Indirect costs:** total productivity costs (short-term and long-term absence, early retirement), changes in employment status of patients and carers, societal losses, disability payments, lost opportunity costs, foregone income due to premature mortality and disability, patient and caregiver time loss, community assistance, home modifications;
- **Intangible costs:** costs associated with pain, social functioning, ability to perform daily activities, anxiety, quality of life, health-related quality of life.

## What is the impact of multiple sclerosis?

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The direct medical costs associated with MS can be considerable. For example, individuals with MS visit the hospital and consultants twice as much as individuals without MS (Naci, Fleurence, Birt and Duhig, 2010). Costs associated with disease modifying drugs vary across Europe, but they typically comprise one of the largest direct medical costs (Naci, Fleurence, Birt and Duhig, 2010). In the UK, however, a small proportion of costs are associated with disease modifying drugs (McCrone, Heslin, Knapp, Bull and Thompson, 2008), although some of those costs are carried by those with MS.

As the disease progresses, some household budgets may be impacted through adaptations that need to be made to accommodate progressing disability. Some examples of such expenses may include the following (Curtis, 2010):

- High dependency home care £1,345 per week, stay at residential home £758 a week, maintenance of special needs flat £933 per week;
- Home adaptations: grab rail £6, hoist £319, stairlift £402, new bath/shower room £1,820;
- Wheelchair (depending on the type) £85 – £390.

The costs associated with lost working capacity are larger costs than the costs to health care and social services (McCrone et al., 2008). A large proportion of MS-related costs accounts for patient and household burden through reduced workability (Battaglia, Zagami and Messmer, 2000). Indirect costs may increase as patients and carers have to change their employment status or even leave the labour market (Phillips and Humphreys, 2009). According to Hakim et al. (2000, as cited in WHO, 2007) who studied the social impact of MS in the UK, 53 per cent of MS patients in the UK who were employed at the time of diagnosis stopped working and for 37 per cent of patients and their families the standard of living declined as a direct result of the disease. As earning power diminishes, it may become increasingly more difficult for patients to afford the direct out-of-pocket expenses associated with MS, which are estimated to be between £1,100 – £2,600 a year (Tyas, Kerrigan, Russell and Nixon, 2007). Financial difficulties may aggravate psychological well-being, as explained by the experts:

*'When someone has been diagnosed with MS, often the occupational aspect of their life changes. Their work role may change, they may have to change their job. They are feeling they are a financial burden, not being able to work. The way the society looks at them is that they are a burden. And it is important what they can put back in the society.'*

A few studies suggest a higher proportion of the costs are attributed to informal care in the UK compared to other European countries, Canada and the US (Kobelt, Lindgren, Parkin, Francis, Johnson, Bates et al., 2000; Naci, Fleurence, Birt and Duhig, 2010). The higher rates of informal care in the UK may be a result of reduced availability of services (Kobelt et al., 2006a). This means that in the UK a considerably burden of the costs associated with MS falls on patients and carers (Kobelt et al., 2000). Caregiver burden measured by caregivers' lost time and foregone income contributes to overall societal costs of the disease (Murphy, Confavreux, Haas, König, Roullet, Sailer et al., 1998). For example, professional careers of 57 per cent of relatives were adversely affected by the patient's MS (Hakim et al., 2000, as cited in WHO, 2007). Assisting MS patients to return to work may therefore benefit both patients and carers, as suggested by one of the experts:

*'If somebody could be redeployed within the workplace and offered alternative work – that would obviously save money in terms of lost employment, but would also have a therapeutic effect. Enable people to cope more and reduce informal care.'*

Additionally, the quality of life of MS caregivers was estimated to be lower than quality of life of diabetic and psychiatric carers: it appeared to correlate strongly with perceived patients' quality of life and was associated with carers developing fear of MS (Alshubaili, Ohaeri, Awadalla and Mabrouk, 2008).

While intangible costs are difficult to quantify (Casado, Romero, Gubieras, Alonso, Moral, Martinez-Yelamoz et al., 2007), an increasing number of studies consider the burden of intangible costs. Some research suggests that intangible costs account for between 17.5 per cent and 47.8 per cent of total costs of MS; the wide range may be the result of the varied approaches to evaluating quality of life (Wundes, Brown, Bienen and Coleman, 2010).

The various costs components highlighted above help illustrate the areas where individuals, the employers, health care system, and society may expect to incur some costs related to MS. Table 3.5 presents the evidence on the costs of MS from the few relevant studies conducted in the UK. Variation in estimations may be attributed to the differences in methodology and sampling method.

As mentioned, MS is unpredictable in its course. Therefore, the costs associated with MS can vary widely by patient. For example, the costs may vary from £12,000 for patients with low disability scores to £60,000 for patients with severe disability stage (Kobelt et al., 2006b). Naci,

**Table 3.5: Comparison of estimations of MS costs, per patient per year**

	Kobelt et al. (2000)	Kobelt et al. (2006b)	McCrone et al. (2008)*	M. Boggild (personal communication, 2011)
Direct medical costs	£2,665	£6,810	£2,164	£8,500 NHS and PSS
Direct non-medical costs		£12,332		
Informal care	£4,373	£9,500	£6,019	£1,635.19
Investments and house adaptations	£1,984	£1,092	£222	£1,886.73
Services (nurse visits, home help, transportation)		£2,832		
Indirect costs (early retirement, productivity loss)	£7,695 (including intangible costs)	£11,174	£4,240	£1,895.18
Intangible costs	£5,170			£9,509.67
Mean	£16,717	£30,263	£12,655	

\*6 months estimate

Fleurence, Birt and Duhig (2008) and Kobelt et al. (2006a) recommend trying to delay the progression of MS to reduce the costs associated with MS.

Due to the significant variation of MS costs between patients with mild and severe disability it is difficult to extrapolate the average per-patient cost of the disease onto a societal scale. One comparative analysis across 30 European countries based on the previous estimation of £30,363 average total costs of the condition per patient (Kobelt et al., 2006b) and the estimated prevalence of 76,851 MS cases in the UK arrives to the **overall cost of €2.4bn (£2.33bn) to the UK society** (Kobelt and Kasteng, 2009). The study gathered evidence from national registries and published sources, as well as self-reported data from a patient questionnaire in order to provide maximally comprehensive assessment of direct, indirect and intangible costs incurred by the disease (Kobelt et al., 2006b).

Our own estimates suggest that the cost to the welfare system of premature loss of work for someone with MS who could have been supported to stay in work might be substantial. For example, we know that – on average – people with MS lose 18 years of working life as a result of their condition (Kobelt et al., 2006a). 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 with MS 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 have been paying in addition.

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**3.6 Conclusion** MS is an unpredictable and fluctuating condition that impacts individuals differently. It affects both mental and physical health. Many of the symptoms are invisible to others and can worsen or improve rapidly. A number of symptoms and co-occurring conditions accompany a diagnosis of MS, including fatigue, depression, incontinence and pain. In the work setting, MS symptoms play a significant role in maintaining employment, but the work environment is also an important factor. Some of the most costly aspects of MS are related to indirect costs, such as the loss in ability to work and informal caregiving. This impacts household finances as well as the greater society. Yet most people who develop MS are of working age and want to work.

Focusing on job retention, with adjustments, could provide both clinical and financial benefits. If people with MS lose (on average) 18 years of working life, and those who are not working have worse outcomes (including higher rates of depression and disability), then clinical and workplace interventions that retain people in employment could greatly benefit not only individuals but also society. The next section will explore what interventions are available to reduce the considerable impact MS has on individuals, families and society.

## 4. What interventions are available for individuals with MS?

No cure is currently available for MS. The interventions provided to individuals with MS seek to reduce the impact it has on their lives. Shortening the duration and impact of the attacks to prevent exacerbation has become one of the main goals of treatment (Ontaneda and Rae-Grant, 2009). Some interventions target the symptoms associated with MS whereas other forms of treatment attempt to slow down the progression of the disease.<sup>17</sup> The interventions available to individuals with MS range from traditional pharmacologic medicines to fatigue management courses and cognitive behavioural therapy (CBT) to vocational rehabilitation. Experts explain that depending on the individual's circumstances the most effective intervention – or combination of interventions – may vary:

*'Interventions are usually targeted. Cognitive behavioural therapy would be most effective earlier on, helping people to cope with the news that they've got MS and early symptoms of MS. As the condition advances palliative care interventions would be more appropriate.'*

To ensure the delivery of interventions at the appropriate time, comprehensive, holistic and integrated care provided by a range of health professionals and stakeholders is needed.<sup>18</sup> Burks, Bigley and Hill (2009) emphasise that in order to address all the consequences of the condition MS care should include both medical interventions and functional treatment through rehabilitation, psychosocial interventions, occupational therapy and social support. Additionally, Rotstein, Hazan, Barak and Achiron (2006) suggest that continuity of care is achieved through a combination of medical and rehabilitation services that matches the development of the disease. This type of care would reduce direct health costs, increase wellbeing and improve employment rates (Rotstein, Hazan, Barak and Achiron, 2006).

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**4.1** As described earlier the costs associated with MS increase as disability progresses. Grima, **Slowing** Torrance, Francis, Rice, Rosner and Lafortune (2000) highlight that the potential for productivity **disease** savings are substantial if disability can be slowed. Therefore, drugs that slow disease **progression** progression may provide benefits to society by avoiding or delaying the severe disease states in which patients are unable to work and become dependent on help from their family (Kobelt et al, 2006a). However, the timing of this type of intervention is difficult with the unpredictable progression of MS. While some suggest earlier intervention may control inflammation associated with MS and prevent irreversible damage, such as cognitive impairment associated with lesion formation (Jeffery, 2002; Gold, Wolinsky, Amato and Comi, 2010; Goodin and Bates, 2009), others suggests that premature start of therapy may exacerbate the comorbidities associated with the condition, which may otherwise develop more slowly or into a benign form (Freedman, 2009).

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<sup>17</sup> Expert interview

<sup>18</sup> Expert interview

Results from one trial by Goldberg, Edwards, Fincher, Doan, Al-Sabbagh and Meletiche (2009) suggest that treatment with disease-modifying drugs reduces the number of clinical relapses and progression of disability. Jeffery (2002) adds that early immunomodulatory drug therapy is effective in reducing lesion formation, which may prevent development of MS-related comorbidities, in particular deterioration of cognitive function. The evidence on improvements in patient quality of life following treatment with disease-modifying drugs is limited, however (Parkin, Jacoby, McNamee, Miller, Thomas and Bates, 2000; Putzki, Fischer, Gottwald, Reifschneider, Ries, Siever et al., 2009). Some experts that we interviewed suggested that slowing down the progress of disease in the early stages may contribute to retention of employment among MS patients.

While only 5.8 per cent of total MS-related costs are attributable to disease-modifying drugs (Kobelt et al., 2006), cost-effectiveness studies by the National Institute for Clinical Excellence (NICE) and other researchers looking at the current therapies available have produced mixed results for the cost-effectiveness of the disease-modifying drugs. However, many of these studies do not account for the societal costs and benefits, and 'value-based' pricing may change the assessment. Tappenden, Chilcott, Eggington, Oakley and McCabe (2004) suggest that the cost-effectiveness of therapies (interferon-beta and glatiramer acetate) adjusted for disability (EDSS) ranges between £39,000 and £92,000 per quality-adjusted life-year (QALY). To make these therapies available to patients, a risk sharing scheme was established which required manufacturers to lower the price of the therapy and to provide continued support for evaluating the long-term effectiveness. Some evaluations of the risk sharing scheme have raised concerns over the clinical effectiveness of disease-modifying drugs (Raftery, 2010). In addition to the costs, the side-effects of disease-modifying treatment include flu-like reactions, abnormalities in blood cell and platelet counts, injection site reactions and episodic depression, for example (Coyle, 2009).

With that said advancements in research and development of treatment for MS provide hope for safe and more effective developments.<sup>19</sup> Growing evidence towards the efficacy of oral agents in reducing relapses associated with multiple sclerosis and avoiding needle phobia (Fox, Bensa, Bray and Zajicek, 2010; Young, 2010) has led NICE to consider the cost-effectiveness of some of those interventions in the UK.

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<sup>19</sup> Stakeholder interview

**4.2** Treatment of MS related symptoms is an essential part of the overall management of the disease (Henze, Rieckmann, Toyka, MSTCG, 2006). Schapiro (2009) argues that it is symptomatic treatment that determines quality of life of MS patient. Several types of medical and complementary interventions are available for symptomatic management of MS. Pharmacological treatments available include drugs targeting pain, bladder and sexual dysfunction, ataxia and tremor, cognitive dysfunction for example (Henze, Rieckmann, Toyka; MSTCG, 2006). While drug treatment and physiotherapy may be more helpful in managing physiological symptoms such as spasticity and pain, there are a range of psychosocial practices that assist patients with coping with the fatigue, anxiety and depression associated with MS (Clegg, Bryant and Milne, 2000). Cognitive impairment interventions research and development is relatively new (O'Brien, Chiaravalloti, Goverover and DeLuca, 2008). However, promising developments from a few studies provide a good foundation for the development of effective interventions (O'Brien, Chiaravalloti, Goverover and DeLuca, 2008).

Rehabilitation has been shown effective in restoring functional capacity of MS patients (for example, Dalgas, Stenager, Jakobsen, Petersen, Overgaard and Ingemann-Hansen, 2010). Interventions such as physiotherapy, resistance training, repetitive training of isolated movements, hydrotherapy, swallowing and speech therapy (Paci, 2003; Henze, Rieckmann, Toyka; MSTCG, 2006) help to reduce spasticity, increase muscle tone and improve dexterity of muscles. However, little evidence is available on the cost-effectiveness of rehabilitation interventions such as physiotherapy (Wiles, Newcombe, Fuller, Shaw, Furnival-Doran, Pickersgill et al., 2001). In a 12-month trial targeted at increasing activity and participation of both patient and family, Khan, Pallant, Brand and Kilpatrick (2008) highlight the value of individualised rehabilitation programmes for reduction of disability and improvement of mobility. A meta-analysis of studies on physical activity among MS patients conducted by Motl and Gosney (2008) reveals that exercise training is associated with a small improvement in quality of life parameters, in particular for aerobic types of training. As mentioned above, the review by Malcolmson, Dunwoody and Lowe-Strong (2007) highlights evidence toward improvements through exercise and movement interventions.

Recent evidence suggests that functional capacity training may have positive effect on psychological wellbeing, reducing fatigue and improving mood and quality of life in patients with MS (Henze, Rieckmann, Toyka; MSTCG, 2006). One trial that provided resistance training to patients reported benefits that were maintained for at least 12 weeks after end of intervention (Dalgas et al., 2010).

## What interventions are available for individuals with MS?

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Individuals with MS must also deal with the demands of managing symptoms on a daily basis, prepare for progressive functional losses and accept the reality of a lack of cure. Frequently, individuals with MS do not receive information to help them cope with their diagnosis (Malcolmson, Lowe-Strong and Dunwoody, 2008) or the progression of the disease. Psychosocial interventions aim to help individuals manage these psychological, social and emotional issues by addressing issues such as low self-esteem and adaptation to the disease and its consequences, in order to improve an individual's ability to cope on a day-to-day basis. A few key points from a review of psychosocial interventions are highlighted below (Malcolmson, Dunwoody and Lowe-Strong, 2007).

- **CBT for depression:** Reductions in depressive symptoms following CBT have been reported in a number of studies. However, definitive evidence of effect is lacking due to methodological weakness in the majority of studies.
- **Group psychotherapy:** CBT and stress management education have been explored in two quasi-experimental studies. Both reported reductions in depressive symptoms. However, methodological weaknesses were also reported (Malcolmson, Dunwoody and Lowe-Strong, 2007)
- **Wellness and support interventions:** Multi-disciplinary team support combined with education, goal setting, homework assignments and discussion forums has resulted in improved quality of life, improved mental and physical health (eg energy/fatigue, bodily pain) and improved emotional wellbeing. Again, some of the studies used small samples and may not work as well in a different setting or with a wider audience.
- **Exercise and movement interventions:** Interventions aimed at addressing exercise and mobility have shown improvements in quality of life and have shown increases in vitality and social functioning. While many studies have methodological weaknesses, the most robust study shows improvement in movement.

Overall the evidence suggests that psychosocial interventions that enable participants to be proactive and provide support through a multidisciplinary team – including peer support – appears to improve psychological well-being and quality of life in individuals with MS (Malcolmson, Dunwoody and Lowe-Strong, 2007).

Additionally, studies of MS psychotherapy groups are helpful in identifying themes that emerge as important for MS patients, including dealing with loss and a sense of being a burden, effective communication with family/carers, low self-esteem, dealing with uncertainty and shame (Askey-Jones, Silber, David, Chalder, Shaw and Gray, 2008).

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Some psychosocial interventions have been reported to complement pharmacological and rehabilitation procedures, for example, bladder and toilet training was used in managing urinal and faecal incontinence (Henze, Rieckmann, Toyka; MSTCG, 2006), and CBT may be successful in reducing pain (NICE, 2003). A pilot trial of an Internet intervention designed to improve goal-setting and increase adherence with prescribed exercise training suggests favourable outcomes for physical activity of MS patients (Motl, Dlugonski, Wójcicki, McAuley and Mohr, 2011).

Similarly, adjustments to work and lifestyle can be made to reduce the impact of fatigue, where it cannot be reduced through other forms of treatment. Energy conservation strategies, such as breaks, communication techniques, and ergonomic adjustments of work environment are recommended to manage the instability of MS patients' performance (Henze, Rieckmann, Toyka; MSTCG, 2006). One patient explains that it is important to identify energy conserving opportunities on a daily basis:

*'I have to pace myself. I have to think if there is something that I'm going to be wanting to do on a particular day and I know it is going to be tiring, then I just have to make sure I don't do much building up to, and I don't have anything major.'*

While the studies above appear to provide evidence toward improvements in symptom management and reduced affects on quality of life outcomes, evidence about the cost-effectiveness of the interventions is lacking. Additionally, many of the studies identified have weaknesses. Therefore, continued research and evaluation through well designed randomised controlled trials will help establish the impact these interventions have on individuals with MS (Malcolmson, Dunwoody and Lowe-Strong, 2007).

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### 4.3 Addressing employment needs

*'People will give up work quite soon really because they are frightened for the future and they feel that they are not going to be able to carry on working.'*

Expert interview

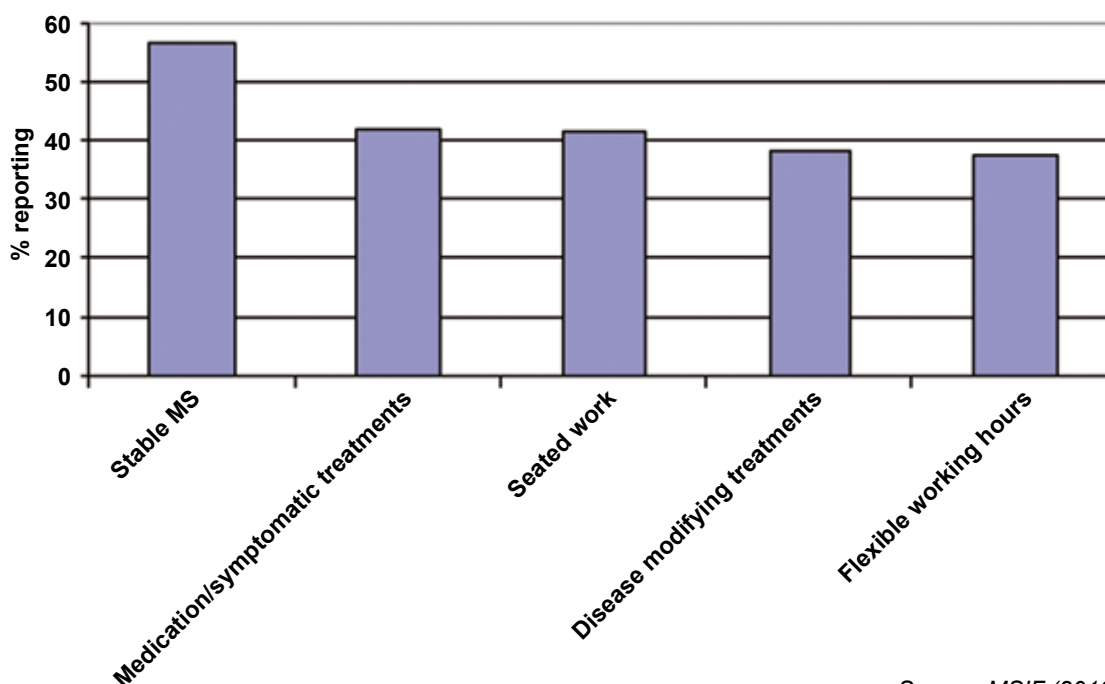
Staying at work may be a challenge for people with MS (BSRM, 2010). As discussed, a number of factors influence outcomes for individuals with MS. Employment and work play an important part in health outcomes providing a sense of purpose, social contact and financial security. However, an individual also has to be in adequate health and receive appropriate health care services at the appropriate time to ensure the experience at work is positive. One of the patients

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explained that *'work is timeout from having MS, as long as it is not impacting in a way that [she] can't manage, it is [a] timeout. And it is another thing of things to think about.'* Lastly, family members and friends can play a role too.

Increasingly, staying in – or returning to – work is being considered as an important clinical outcome for individuals with MS.<sup>20</sup> This is reinforced by changes to the NHS Outcomes Framework mentioned earlier. However, decisions about work need to be considered on a case-by-case basis. For some, work may not be possible or the best outcome. Work needs to be good work to provide benefits to individuals with MS. In addition to the work environment, as mentioned in Section 3, MS-related factors greatly contribute to an individual's ability to remain working. Figure 4.1 below illustrates this point and presents results from a worldwide study from the MS International Federation (MSIF, 2010) about employment and MS.

**Figure 4.1: The top five factors that enable employment for people with MS (N=3,792)**



Source: MSIF (2010)

Family support (60 per cent) and supportive employers and colleagues (49 per cent) further enable individuals to remain in work (MSIF, 2010). According to those who left work, the main factors that would have helped people remain in work would have been the following (MSIF, 2010):

<sup>20</sup> Stakeholder interviews

## What interventions are available for individuals with MS?

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- Flexible working hours;
- Scheduled work breaks with a place to rest;
- Improved awareness of MS among colleagues;
- Increased support from employers and colleagues.

Many of these factors were important to both individuals with MS as well as carers (MSIF, 2010). The stakeholder interviews highlighted these factors as well. Additional supportive workplace factors include improving the physical environment – making the workplace more accessible and making it easier to access toilets more quickly.

The interventions available to assist individuals with MS vary widely and can frequently depend on the individual offering the intervention.<sup>21</sup> Individuals with MS have had mixed experiences with the type of support they have received (Townsend, 2008), largely, lack of support results from poor understanding about MS – particularly the invisible symptoms:

*‘Some patients would be accused of being lazy because of the fatigue. Some people will take it head on. Other colleagues would not necessarily know what it is.’*

Expert interview

Stakeholder interviewees mentioned how it would help for someone to assess the work environment and offer adjustments specific to that person. BSRM (2010) estimate that 98 per cent of public and 36 per cent of private sector employees have access to an occupational health specialist who would be able to assist with assessment of fitness for work prior to recruitment, evaluation of fitness on return to work, as well as health and safety management. The review outlines a number of employee advice programmes available, for example, through Jobcentre Plus.

Yet, some people with MS may be unlikely to seek occupational help until an employment crisis develops (LaRocca, Kalb and Gregg, 1996). However, with the unpredictable and fluctuating nature of the condition proactively planning ahead may avoid leaving or even losing a job during a difficult time, as explained by one of the experts:

*‘Invariably, persons with MS are the first ones to be made redundant. Fluctuating nature and chance of major relapse may be a reason for sacking them, but maybe they should reconsider the role instead.’*

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<sup>21</sup> Stakeholder interview

## What interventions are available for individuals with MS?

Disclosure of MS is of particular concern in the employment environment. Fear of losing a job following disclosure of the condition to an employer is a significant obstacle to continued employment (Roessler and Rumrill, 2003; Johnson et al., 2004), particularly in association with the decrease in cognitive ability (LaRocca, Kalb and Gregg, 1996; Smith and Arnett, 2005). Additionally, they may worry about discrimination (Halper, 2007). One of the patients admitted fear of being overlooked for challenging tasks:

*'I think I probably have to make people more aware... Obviously I have a bit of fear doing that but I have a bit of fear doing that because I don't really want to affect my job. I don't want it to be that I am passed over and kind of disregarded because I have problems.'*

People with disabilities are rarely taught how to communicate with others about the associated stigma (Halper, 2007). Individuals with MS may worry about their ability to continue working and may feel the need to work over and above to prove that their condition is not impacting their work.<sup>22</sup> Each individual's circumstance needs to be considered as disclosure can have benefits as well as costs. On the other hand, explaining the condition to managers and co-workers may be a relief:

*'People struggle because they don't tell anybody. If their managers are aware, they've got a commitment to make sure that the patient is safe within the work environment, they have to make reasonable adjustments to the workplace. People often worry about telling their managers, but once they've told them, they find it's weight off their shoulders.'*

Stakeholder interview

Some resources from MS patient advocacy groups are available to help with decisions about disclosure.<sup>23</sup> Additionally, MS occupational specialists and MS specialist nurses can help. By disclosing individuals are more likely to obtain reasonable adjustments and access to schemes like 'Access to Work'. The Access to Work scheme makes it possible for someone with MS to take a taxi to work in order to minimize exertion related to travel to work. One stakeholder described this programme as the '*government's best kept secret*' because awareness about the programme is lacking. Another stakeholder also highlighted the lack of awareness and the changes that are occurring to the scheme:

*'Majority of employers unaware of Access to Work. But that is less supportive now since they will change what they will supply....For people with MS, retention is one of things*

<sup>22</sup> Stakeholder interviews

<sup>23</sup> For instance: <http://www.yourworkhealth.com/> and <http://www.mstrust.org.uk/information/publications/atwork/> and [http://www.mssociety.org.uk/support\\_and\\_services/free\\_publications/working\\_worried.html](http://www.mssociety.org.uk/support_and_services/free_publications/working_worried.html)

## What interventions are available for individuals with MS?

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*you would look at as being one of the most appropriate actions rather than looking for new work. And Access to Work is about the only governmental support towards work retention. Everything else is aimed toward getting a job when unemployed on benefits.'*

Stakeholder interview

While evidence about the effectiveness of vocational rehabilitation programmes is inconclusive (Khan, Ng and Turner-Stokes, 2009), BSRM (2010) outline the following recommendations for vocational rehabilitation for people with long-term neurological conditions including MS, in regards to facilitating their participation in employment:

- Management of health conditions and consequences – addressing mobility issues, cognitive and emotional difficulties;
- Environmental adaptations;
- Anticipation of the dynamics, eg with age, with progress of disability;
- Access to vocational experts and ability to respond quickly;
- Established links with voluntary/user led organisations.

Focus groups conducted with MS patients revealed their need for vocational rehabilitation, including adjustments of physical environment and work demands to the impact of MS, as well as increased awareness of the relevant legislation and counselling in supporting MS patients in their work and family lives (Sweetland, Riazi, Cano and Playford, 2007). Particular expectations of employers named by the participants included the following (Sweetland, Riazi, Cano and Playford, 2007):

- Improving performance (for example, providing rapid access to physiotherapy);
- Compensating for changing performance (moving desks closer to toilets, or providing transportation to workplace);
- Modifying performance (allowing flexibility of work patterns);
- Advocacy and support with disclosure.

Similarly a large survey across 18 European countries conducted by Uccelli, Specchia, Battaglia and Miller (2009) suggests that external factors impact on patients' decisions about staying at work rather than solely the specific health symptoms or disease worsening. The significant parameters related to the work environment that supported employment among MS patients could be divided into the following three groups (Uccelli, Specchia, Battaglia and Miller, 2009):

## What interventions are available for individuals with MS?

1. Workplace accessibility: seated work, adequate environmental temperature, elevator, accessible/conveniently located work area, equipment and bathroom, accessible transportation and parking.
2. Job flexibility: flexible work schedule, possibility to set your own pace, intermittent breaks/rest, assistance with work, limited distractions, single-task job, routine work or workload, varied tasks, job performance expectations, seniority, freedom to take time off when needed, stable workgroup (limited turnover of co-workers/colleagues).
3. Financial security: employment policy/benefits, pension or retirement policy/benefits, current salary, future financial stability.

While many patients report that their employers have been extremely helpful in agreeing to adapt their job to better suit their needs, providing changes to the number of hours, allowing more flexibility in work, changing jobs completely, or making adaptations to the physical workspace, to support of MS patients may not always be easily implemented (Staley and Hanley, 2006). Roessler, Rumrill, Hennessey, Vierstra, Pugsley and Pittman (2003) find that MS patients are concerned about knowing their rights regarding available employment and social services, fair treatment and provisions for flexible working. MS specialist health professionals play an important role in navigating patients through the various interventions, schemes and resources available to them.<sup>24</sup>

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### 4.4 The role of MS specialist health professionals

Throughout the stakeholder interviews, the role of MS nurses and other allied health professionals has been described as key to the delivery of integrated care. Additionally, NICE (2003) provides guidance that emphasises how MS nurses support patients by providing information about the disease, as well as formal and informal emotional support. Similarly Malcolmson, Dunwoody and Lowe-Strong (2007) report that wellness and support interventions, such as coping skills group, multidisciplinary team (MDT) support and telephone support, contribute to better mood and overall satisfaction, positively impact physical and mental health, reduce pain and fatigue and helped expanded the range of social roles. MS nurses frequently play a role in developing or referring patients to these types of interventions when they are available.<sup>25</sup> One stakeholder's description of the role of an MS nurse is below.

*'Nurses usually will see patients on a regular basis. They will build up a rapport with patients and understand variation in approaches from one patient to another. They will also have had experience of other patients in similar positions. They will often be the lynch pin in terms of referral to access to work, for example...so that patients can get*

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<sup>24</sup> Stakeholder interview

<sup>25</sup> Stakeholder interview

## What interventions are available for individuals with MS?

*transport to work and to keep people in work, which is really important, not just financially, but personal prestige, giving structure to their day, and allowing them to interact with other people who aren't unwell.'*

Results of the MS Society survey indicate that for 91 per cent MS patients in the UK their nurse is the first point of contact regarding their condition (Heinonen and Dorning, 2011). Currently there are around 220 MS specialist nurses in the UK<sup>26</sup>, although there is a variation in access to nurse care between urban and rural areas (Johnson, Goldstone and Smith, 2001). One of the patients highlighted the role of MS nurse in managing the condition:

*[I feel ] 'lucky to have MS nurses that cover the region. I go to see one of those. She is really good... she will give some quite good advice, things I should do and try and things that might help me. She liaises with the neurology department at the hospital.'*

At the same time there is little health economic evidence toward the value provided by specialist MS nurses in improving clinical and psychosocial outcomes for patients with MS (De Broe, Christopher and Waugh, 2001). Health Technology Assessment report commissioned by NICE reports costs of providing MS specialist nurses to add up to £40,000 yearly, which is based on nurse's yearly salary, costs for travelling, administration, computer and telephone use, a pension scheme, National Insurance and study leave (De Broe, Christopher and Waugh, 2001). However, this cost could likely be offset by MS specialist nurse generating a net saving of over £64,000 in a year from reductions in admissions to the hospital.<sup>27</sup> Threats to cut the number of MS nurses under the review of the health care system may hinder access to specialist support for many MS patients. Many of those we interviewed were extremely concerned that any erosion of MS Nurse numbers would threaten a highly valued and effective link in the already vulnerable chain of care for some people with MS.

While it is difficult to accurately express the impact of nurse care in QALYs or disability-adjusted quality of life (De Broe, Christopher and Waugh, 2001), anecdotal data suggest that patients feel less embarrassed to talk to specialist nurses about sensitive health issues associated with MS (Campion, 1997).<sup>28</sup> Continuity of communication with an MS nurse has contributed to improved management of the condition through personalised lifestyle plans (Wilson, 1998). Kirker, Young and Warlow (1995) reported improvements in patients' knowledge of MS, coping, mood,

<sup>26</sup> <http://www.msnc.co.uk/index.cfm/fuseaction/show/pageid/2329>

<sup>27</sup> <http://www.msnc.co.uk/index.cfm/fuseaction/show/pageid/2329>

<sup>28</sup> Also mentioned in stakeholder interviews, additionally patients highlighted how they valued their relationships with their MS specialist nurses

confidence, life in general and family relationships, as well as psychological reassurance among patients seeking MS nurse support.

Patient education and advocacy are under increasing scrutiny in MS management (Shevil and Finlayson, 2010). Information is empowering – appropriate information on alternative treatments helps with coping – this may come from MS courses and MS specialist nurses (Malcomson, Lowe-Strong and Dunwoody, 2008). In addition to specialists a valuable source of support also comes from patient advocacy groups and peers.<sup>29</sup> Sharing experiences and learning from others can be particularly helpful. A qualitative study about what individuals with MS want highlights the importance of peer support and ‘expert’ patients (Malcomson, Lowe-Strong and Dunwoody, 2008).

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**4.5** The evidence above highlights the various options available to individuals with MS.  
**Bringing** Interventions range greatly. Depending on the individual situation one intervention may be more  
**it together** preferable than another intervention. Frequently, a combination of interventions is needed to provide optimal care. While the evidence for some of the interventions above is lacking, they do provide support for developing a holistic patient-centred package of care (Malcomson, Lowe-Strong and Dunwoody, 2008).

For example, a cohort study of patients participating in care management programme (Tan, Yu, Tabby, Devries and Singer, 2010) has shown that medication adherence and persistence improved among participants but deteriorated among non-participants. Hospitalisation rates associated with MS complications decreased from 9.6 per cent to 7.1 per cent for those in the programme, reducing medical spending by US\$264 as compared to expenditure prior to the programme. The MS-related costs of non-participants have increased by US\$1,536 over the same period of time (Tan et al., 2010).

Once interventions like these are developed and offered to individuals with MS, evaluations need to consider a wide range of outcomes – including the ability of the MS patient to remain in employment as prior to diagnosis. More evidence about the effectiveness of the wide range of interventions could provide stronger support for demonstrating the cost-effectiveness of these interventions. Importantly for individuals with MS, interventions need to focus on providing the best care to improve health outcomes, but also encourage continued functioning. Discussions about employment should occur throughout the provision of care.

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<sup>29</sup> Stakeholder interview

## What interventions are available for individuals with MS?

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Recently, the arthritis patient community in both the UK and Europe developed a 'Charter for Work' geared toward policymakers, employers and health professionals.<sup>30</sup> This type of intervention recognises the various stakeholders who can play an important role in enabling individuals with chronic health conditions to remain in or return to work. A similar charter could be developed for MS, which could help empower individuals, policy makers, employers and health professions to begin or continue discussions about needs at work by taking a comprehensive and holistic approach to MS.

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**4.6 Conclusion** A number of interventions and resources are available to individuals with MS. In some instances these are co-ordinated and effective, but in other instances they are lacking. In order to provide optimal care to individuals with MS, more needs to be done to establish which interventions provide the most benefit and at what time. Overall more research and evidence is needed to determine which interventions maximise quality of life and workability of individuals with MS. However, it is widely acknowledged that a holistic approach to care that incorporates the medical, psychological and social aspects related to MS is needed. MS nurses and other allied health professionals play a vital role in coordinating care and referring patients to the appropriate resources. Interventions that help individuals with MS become good self-advocates and manage disclosure discussions may be particularly helpful in the employment setting. Additionally, changes in the workplace, such as more flexible working and adjustments that provide easy access to the building and toilets will enable individuals with MS to continue working. By providing optimal interventions at the appropriate time, further disability and reductions in quality of life and workability may be avoided.

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<sup>30</sup> Stakeholder interview. A work charter has been developed in the UK and in Europe; The European 'Charter for Work': <http://www.eular.org/myUploadData/files/EULAR%20Charter%20for%20Work.pdf>

## 5. Conclusions, recommendations and a call to action

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This report has highlighted 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 fulfilling working lives.

Too often, Multiple Sclerosis (MS) is a 'hidden disease' and this lack of visibility hinders the ability of individuals to accommodate the fluctuating and unpredictable nature of their condition in social and employment settings. Many have to change jobs or even retire early after the onset of disease, putting a strain on households and the economy. Furthermore, long periods of unemployment and difficulties in finding jobs undermine individuals' self-esteem and may negatively affect mental well-being. Supporting MS patients in job retention and return to employment has important individual and societal implications.

While there is currently still no cure for MS, most of the currently available interventions seek to slow down the progress of MS and reduce the impact of symptoms on daily activities. Social and psychological care as well as employer interventions may provide invaluable benefits for coping with symptoms that affect patients' quality of life at various stages of the disease.

At the same time, employers are not experienced in managing unpredictable changes in the performance of employees with MS. Consequently, such patients fear to disclose their conditions at work as job loss may seem to be a likely outcome. On the other hand, simple workplace adjustments, such as flexibility of working hours or technical aids, could prevent individuals from leaving work prematurely. Most MS patients are 'grateful' if they have a job, and supportive work environment is a crucial factor in their employment decisions.

There is evidence that better quality jobs – with control, autonomy, flexibility and discretion – have a positive impact on health outcomes. But individuals with MS face numerous threats and challenges, such as dealing with uncertainty and unpredictability and the ensuing changes in family, employment and social life. Job retention is one source to support self-esteem of MS patients.

However, health care systems and social policies may not always be fit to the needs of the patients with long-term conditions. With recent focus on retaining people in work, both health professionals and employers need to see job retention as an outcome and encourage phased return to work of MS patients, by making more effective use of Fit Notes.

**Educate,  
research and  
co-ordinate**

This research has identified three areas where effort needs to be intensified if the position of people with MS in the UK labour market is to be improved:

- 1. Educate:** Universally, increased awareness about MS is needed throughout society. This includes the health care system, employment system and welfare system. The symptoms of MS are frequently hidden. They include both mental and physical impacts. While someone without MS may have an idea about what MS is, they may not understand exactly how it feels for someone with MS. The fatigue can be particularly difficult to understand. Failing to recognise how fatigue may impact someone may lead to insensitive comments and may also risk pushing someone too hard. If someone seems fine one day, but overworks, the next day that person may not be able to work nearly as efficiently. The fluctuating nature of the condition makes this difficult. Awareness about MS among employers and work colleagues needs to improve, as well as their recognition about the symptoms that may impact individuals with MS. Additionally, multidisciplinary teams of health care professionals need to help newly diagnosed individuals adjust to their condition, and this includes providing them with information which helps empower them when they have discussions about continuing work.
- 2. Research:** More research is needed to evaluate the clinical effectiveness of interventions. Many interventions described in this report, although do not promise an immediate cure for MS, seem to significantly improve the lives and workability of individuals with MS. However, the cost-effectiveness, and in some cases the clinical effectiveness, of these interventions is not well established. In order to provide optimal care to individuals with MS, more needs to be done to establish which interventions provide the most benefit and at what time.
- 3. Co-ordinate:** It is clear that more co-ordination through all aspects of care is important. Regular monitoring and adjustments help to provide an opportunity for providing optimal intervention at the appropriate time. Furthermore, navigating the welfare system and learning about the resources available can be difficult. Someone who can help signpost these resources can ensure individuals take advantage of the resources available to them. Co-ordination through the health care system, welfare system and employment system is also needed. Individuals need to receive appropriate health care, but also need to maintain employment in jobs that support good work, to fully benefit from continuing to work. Those who are already receiving welfare benefits, but who are at risk for losing those benefits, need support from a variety of sources to find appropriate jobs. A bad job can aggravate health outcomes. Therefore, employers need to provide

good working conditions and reasonable adjustments with the help of occupational health professionals. Establishing a work charter might be one tool to improve co-ordination. Holistic, well co-ordinated care that involves a variety of stakeholders can improve outcomes for individuals with MS.

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### A call to action

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.

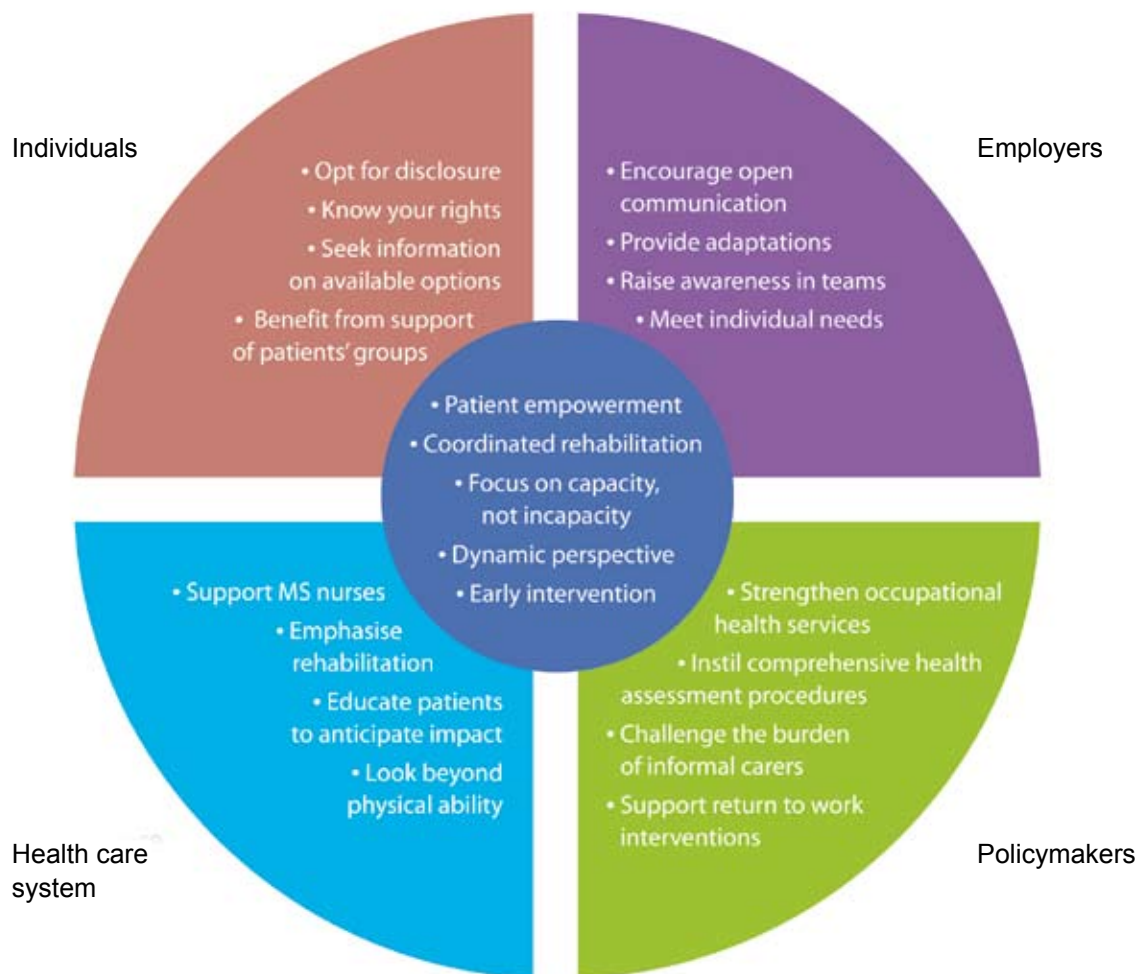
A range of stakeholders must work together to reduce and prevent the impact of long-term health conditions on the ability of individuals to remain at work. One example of best practice in establishing co-operation of individuals, employers, health care providers and policy-makers in reducing the cost 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 co-ordinated 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.

## Conclusions, recommendations and a call to action



**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.

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

- Co-ordinate 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.

**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 co-ordinating 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.

Work opens doors for people and can provide income, a sense of purpose, dignity and social connectivity. This report has argued that, with more co-ordinated action the majority of people with MS who want to work can be kept in full and fulfilling employment.

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## Appendix 1: Stakeholder interviews

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We interviewed or consulted the following people during the course of our research and we are very grateful for the time each spent with us. We have taken their views into account in writing this report, though their participation in the study does not in any way imply endorsement of the report's conclusions.

Liz Betts	MS Specialist Physiotherapist
Mike Boggild	Consultant Neurologist
Lynn Fox	MS Trust
James Gray	MP, All Party Parliamentary Group for MS
Ed Holloway	MS Society
Alison Johnson	MS Specialist Occupational Therapist
Hayley Jordan	MS Society
Annette Leach	MS Specialist Nurse
Stephen Lloyd	MP
Gordon Matizaba	Consultant Neurologist
Paul McCrone	Professor, King's College London
Debbie Quinn	MS Specialist Nurse
James Raftery	Professor, Southampton University
David Rog	Consultant Neurologist
Sally Thompson	MS Specialist Nurse
Gail Townsend	MS Specialist Occupational Therapist
Sarah Westlake	MS Society, Work Life Website Editor
Helen Yates	MSRC
Freddie Yauner	MS Shift

In addition, we spoke with a three individuals who have been diagnosed with MS to learn about their experiences. We are grateful for the time they spent with us.

## Appendix 2: Secondary data analysis results

Descriptive statistics from secondary data analysis

<b>MS diagnosis</b>	<b>%</b>	<b>Number</b>
Relapse-remitting	72.2%	140
Secondary progressive	17.0%	33
Primary progressive	5.7%	11
Do not know	5.2%	10
<b>Gender</b>		
Male	21.1%	41
Female	78.9%	153
<b>Employment status</b>		
Employed	52.1%	101
Self-employed	5.2%	10
Home maker	9.3%	18
Retired due to age	1.0%	2
Retired due to MS	23.2%	45
Student	3.1%	6
Unemployed	6.2%	12
<b>Age</b>		
Average age	43.6	
Average age of diagnosis	34.9	
Average age of first symptoms	29.9	

## Appendix 3: Measures to evaluate disability associated with MS

Currently the set of measures available to evaluate the effect of MS therapies includes relapse rate, Expanded Disability Severity Scale (EDSS) and the MS Functional Composite (MSFC). The latter two measures attempt to provide a complex assessment of the impact of the disease on various body systems, as well as changes in three critical elements of MS disability: ambulation, arm function and cognition (Phillips and Humphreys, 2009). Consistency of these scales remains a subject to debate, however the measures appear to be appropriate to use at least in randomised clinical trials (Cheng, Crandall, Bever, Giesser, Haselkorn, Hays et al., 2010). The two measures are described in more detail below.

**Expanded Disability Severity Scale (EDSS)** is a scale of assessment of disability among MS patients most commonly used in MS trials (Kurtzke, 1961; 1983). The EDSS quantifies impact in eight functional systems: vision, brainstem, pyramidal, cerebellar, sensory, bowel and bladder, mental (cerebral) and other, with a score of 1 (no disability) to 10 (death of MS) assigned to each category. Stages above 5 are additionally characterised by impairment to ambulation.

EDSS scale is criticised for the ordinal nature of scoring with unequal sized steps which are not very sensitive to clinical changes that do not impair gait (Pryse-Philips, 2001).

**MS Functional Composite (MSFC)** attempts to provide a more consistent instrument for measuring functional disability through introducing a single measure for all variables examined (Z-scores) and provides additional information about patient's cognition status.

Source: US National MS Society. [www.nationalmssociety.org](http://www.nationalmssociety.org)

## Appendix 4: Patient case studies

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### Case study 1 **Administrative worker in a knowledge-based organisation, diagnosed recently with benign MS, female.**

Participant A works in an administrative role at a knowledge-based organisation. She is good at what she does. Participant A *'enjoys'* her job and the challenge it offers. She also enjoys the social aspects that the job offers. Participant A thinks she would be really bored if she could not work. Another important reason for working is financial. Participant A needs to work.

Over the past year, the organisation where Participant A works has undergone significant change. She now has a number of new colleagues. Her work patterns and roles have also changed. As someone with experience and knowledge about the history of the organisation, she is highly valued. Many of her colleagues approach her with questions, and Participant A helps point them in the right direction. Right now, Participant A works full-time and sometimes works even more hours. She has had a hard time finding the right balance between work and life.

*'It is quite hard to get the balance right. I mean I would say at the moment, I don't have a good work-life balance. But I would not want to give up my job. But I think if, maybe, I could drop say from 5 days to 4 days, it would perhaps make me better outside work to do other things. You know kind of like the best of both worlds, if I could manage to cut my hours down a bit. But I am not sure how practical that is to be honest.'*

Participant A was diagnosed quite recently. But she experienced a problem about 10 years ago, which was thought to be something else. The experience was quite dramatic, but did not last too long. At that time, she did leave her job for a bit to build back her strength. Her second experience was similar to the feelings from before, but it lasted a lot longer and was not quite as sudden. Instead, it gradually got worse. She felt pins and needles in her fingers, which then developed to numbness. Her GP referred her to a neurologist. It progressed as the neurologist was doing tests. She had an MRI that indicated that it might be MS, and a lumbar puncture confirmed MS. Participant A feels lucky that her symptoms appear to have reached a plateau. Participant A says that *'most people wouldn't know [she] had a problem.'* The symptoms of numbness worsen as she becomes more tired. The key is to pace herself.

Participant A has told a few of her colleagues at work about her diagnosis. Most have been sympathetic. Participant A told the HR manager, and she *'glad'* to tell her because she will be a good advocate for her in the future, if she has difficulty. The HR manager also tries to ensure she goes home at a reasonable hour. Another colleague has a family member who has MS and is very sympathetic to Participant A too.

## Appendix 4: Patient case studies

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Her previous line manager gave her time off for medical appointments and allowed extra time off to make up for instances where she worked extra hours. Her new line manager, however, *'does not quite grasp the problem'*. Participant A thinks she will have to make her new line manager more aware, along with a few other colleagues. Occasionally, Participant A feels a bit resentful when team members are not *'pulling their weight'*, because it often means she needs to pick up more work. Also, her new line manager does not quite understand how difficult working long hours can be for her. Participant A recognises that she will need to speak with him more about her needs, but worries about how this might impact her.

*'I think I probably have to make people more aware... Obviously I have a bit of fear doing that but I have a bit of fear doing that because I don't really want to affect my job. I don't want it to be that I am passed over and kind of disregarded because I have problems.'*

Participant A tries not *'to let the illness affect [her] work.'* She works hard and achieves her work, and if she needs to, she works extra hours to get it done. In fact, Participant A has probably *'taken less time off because of MS to prove a point that [she is] ok and can do the job.'*

Participant A feels that the biggest impact that MS has had on work is the sensitivity she experiences in her hands. She frequently uses the computer, but does not feel the keys. So, while she can use her hand and fingers, not being able to feel the keys slows her down a bit. Participant A also has to rely more on her vision, because she can not do things by touch. For instance, judging how hard to push a button can be difficult.

Her family has been supportive. For instance, they drive her to and from places, which can be particularly helpful. In fact, they can occasionally be over supportive and protective. Her relationship with her partner has changed as a result of her diagnosis.

*'With my husband things have had to change quite dramatically. In that because my fatigue sometimes becomes a problem. I will go to work and I will put in 100 per cent at work but then I come home and that's it. I am finished, and I can't really do much more. Traditionally it's always me who kind of did the cooking, the shopping, the cleaning, and really he has taken over a large part of that. He does most of it, because physically I just can't do it. And it makes me feel quite guilty because I think he works full-time too. He has a lot on his plate. It adds to the burden on him.'*

Participant A has also had to limit some of the social activities that she used to partake in with her partner. She has also been limited in the amount of travel she can do, which impacts her ability to see extended family members. The fatigue has been what limits her participation. She tries to plan her time.

*'I have to pace myself. I have to think if there is something that I'm going to be wanting to do on a particular day and I know it is going to be tiring, then I just have to make sure I don't do much building up to, and I don't have anything major planned afterwards.'*

An MS nurse has been helpful in providing support and guidance, which Participant A feels fortunate about.

*'[I feel ] 'lucky to have MS nurses that cover the region. I go to see one of those. She is really good... she will give some quite good advice, things I should do and try and things that might help me. She liaises with the neurology department at the hospital.'*

In particular, the MS nurse has been helpful as a source of advice. Participant A also feels that the MS nurse helps her cope some with her depression. She feels that the MS nurse has a good specialist understanding about her condition, which would be missing from a counsellor who does not know the specifics of the condition. Participant A feels that the MS nurse helps 'put things in perspective a bit.'

At work, Participant A has not made any specific changes. However, Participant A would really like to move to a part-time position. She recognises that the timing of this request is important due to all the changes that have occurred at her workplace and the role that she holds. She thinks in time, this will be a good option. However, she does worry about what might happen.

*'If it is not feasible for me to work part-time where I am, the difficulty is that it's not really feasible for me to go somewhere else and work part-time. Any new employer wouldn't know my worth. [They] would look at that and say no, she has got some illness, we don't want her. That is the reality of life... I am with a company that is a really good company and I do feel that they value me. I am trying to come up with a solution...[and] picking the right moment to tell them.'*

**Case study 2 Professional, knowledge worker, diagnosed with relapse-remitting MS about 10 years ago, female.**

Participant B worked in a highly paid profession prior to being diagnosed with MS. Now, Participant B works in a different role that combines some of the skills of her previous profession with something she finds '*fascinating*'. The reasons that Participant B goes to work is for the '*challenge*', the social contact, and the opportunity to do '*something worthwhile*.'

An ideal day would allow for her to accomplish everything on her agenda. However, much of the time Participant B assists team members with their queries. Some team members can be '*quite demanding*' and frequently she has to respond to needs as they come up. Therefore, Participant B does not have a lot of control over her day.

Participant B's MS symptom's started in her late teens. She then had a relapse about 5 years later. At that time, her GP thought it might be migraines. Participant B continued without a diagnosis for another 15 years before having her first major relapse. She experienced very blurred vision, which was similar to what she had about 15 years earlier. However, it did not go away as quickly. She went to her GP. When he saw Participant B walking he realised she likely had MS. He sent her to the hospital for an MRI where they confirmed she had lesions on her brain. However, the specialists needed to rule out a few other diagnoses before confirming her diagnosis. About a year later, when she had another relapse the diagnosis of MS was confirmed.

Initially the MS did not impact her day-to-day life. The first thing that really started to affect her was fatigue. About a year later, she started to experience considerable pain.

*'As time has gone by the impact on my day-to-day life is increasing...I don't go out as much as I use to. I don't work full-time. I do realistically struggle to go into work. I don't do much exercise. I used to be someone who always prepared a meal every evening, but I don't do that any more. I some times have a cleaner to come in to help clean...Life is more about getting me through each day.'*

At work, she describes that '*things went terribly wrong around the time of [her] diagnosis*'. While she was still waiting for a confirmed diagnosis, Participant B had a number of conversations with managers in her office. They were interested in retaining her because she had a history of doing good work. During this time, Participant B was terrified because she was not sure what

was going on with her. When Participant B did receive a diagnosis, she talked with HR about her needs for some time off initially, followed by staged return to work and doing some work from home. She felt reassured that everything would be fine, but then there were changes in her department. They were also confused by her diagnosis and how it might impact her. They talked to her about resigning from her position, which she refused. In the end, she was made redundant.

For a while, she was self-employed, but then started to run out of money. Due to the experience from before, she could not return to her previous sector so she decided to change careers. Participant B had a few choices after interviewing for a several jobs. She chose the job that was closest to where she lived. Participant B declared her disability when applying for the position, and when she started work the head of the department knew that she had MS. Participant B told all of her colleagues and she has felt lucky that a number of colleagues knew others who had MS. There was a *'real body of knowledge about MS around her.'* With that said, *'they know in theory but don't know in practice.'* While many have been helpful and supportive, she described an instance where one colleague told her to *'buck up'*, which Participant B felt was insensitive.

Participant B started this new role full-time, but realised she was not coping with it. She engaged an occupational health professional to find out what adjustments might be available. They decided that part-time work with one day working from home per week might help. Participant B continues to work with these arrangements. However, she feels that it would be better if she could work from home more regularly. Participant B has an informal arrangement with her current line manager to call into the office if she needs to work from home one extra day per week. With the present economy Participant B is not sure whether asking for a more formal arrangement of working from home two days per week would be feasible. She also feels it could put her at risk of losing her job. By working more flexibly at home Participant B does not have to travel into work, put make up on in the morning or do her hair. All of this allows her to pace herself better.

In addition to family who have been supportive though everything, Participant B recognises that her job and colleagues have helped her through some difficult times, particularly when her partner left her. They made her laugh and gave her an opportunity to think about something else. Participant B explained *'work is timeout from having MS, as long as it is not impacting in a way that [she] can't manage, it is [a] timeout. And it is another thing of things to think about.'*

## Appendix 4: Patient case studies

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However, Participant B also acknowledges that people with MS, herself included, are very grateful to have a job and that they are frightened a lot of the time. This 'probably impacts on... health in the long term.' Participant B has had to be a strong advocate for herself, and learn to manage herself as well.

Participant B is in the process of applying to 'Access to Work,' which will provide help for part of her journey to work. Additionally, Participant B has made some specific adjustments at home and in the office to help her remain in work. For example, an occupational therapist worked with her to figure out how she spends her day to help manage her fatigue levels. They went through an entire day from the moment she woke up to the moment she went to bed. From this exercise, Participant B realised that she did not have to make her bed every morning, for instance. She also organised her movements in the morning to limit the amount of steps she takes and added a seat to her shower so she can sit down when she is washing her hair. All these pieces of advice have proven very helpful to Participant B.

What would be really helpful to Participant B would be the opportunity to truly work flexibly in her job. Currently her three day weekend is very helpful because it gives her time to rest to get ready for the work week. If she worked at home and then went into work when she wanted to, she feels managing work would be much easier.

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### **Case study 3 Self-employed administrative worker, diagnosed about 5 years ago with relapse-remitting MS, female.**

Participant C works part time and is self-employed. She works very independently and flexibly. The main reason she has her current job is because of her illness. Before being self-employed Participant C worked full time in a completely different role.

*'I did not work for myself before. I did not do this job before. [But] I worked for a company that failed to make reasonable adjustments...that is why I had to change. The stress levels were immense and they were making my illness worse really. I decided to walk away.'*

Participant C likes to work because it 'keeps [her] brain going' and gives her a sense of purpose. She feels that work is good for her.

*'I like to work and enjoy new challenges...even though I've got the illness, I do try and sort of stay in that big wide world out there.'*

Participant C was diagnosed about five years ago. A routine eye check-up revealed a problem with one eye. She received a letter to go to the hospital which then led to a brain scan where an MS relapse was listed as a possibility. About a year after test she was officially diagnosed with MS.

The main symptom was optic neuritis, but she had experienced pain her head which she thought may have been a tension headache. Her diagnosis had an impact on her day-to-day life. Participant C feels that her self confidence and self-worth have been affected by her diagnosis. Additionally, changes in her employment status have changed her financial status as well. Participant C was 'shocked' when she was diagnosed and felt 'scared' and 'angry.' Now, she is not as angry about her diagnosis, but does feel frustration occasionally.

*'Frustrated that people don't really know what it is like for me. Even though I am walking around doing everything, it is hard sometimes because it does knock your confidence.'*

In general Participant C thinks that some people may not fully consider the impact her condition has on her.

*'People don't know much about it. Because I am well people take it for granted that I can do everything. But I can't do everything because my energy levels don't always let me.'*

Before changing her job, she told her employer about her diagnosis. Some colleagues were nice and sympathetic, but some were not very understanding about her diagnosis. The employer did not make reasonable adjustments, and Participant C thinks that they could have been more understanding. Additionally, her employer did not understand the legal obligations, which made things even more difficult. Participant C had to be a strong self-advocate, but in the end decided to change her employment situation. Now, she has a lot of flexibility in her work and does not feel as much pressure.

*'Because I work from home and even if I am in the office...I am never put under any pressure to do things. If I am having a bad day, they can see that...But I can juggle it about because it is flexible. It doesn't matter what day I work or when.'*

## Appendix 4: Patient case studies

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Participant C's family has been supportive. Additionally, she has received good care from the health professionals that she has worked with and she feels fortunate to have good care.

*[The] 'treatment from the neurologist, the eye specialist and my MS specialist nurse have been fantastic...It has been good. I have been fortunate maybe, I don't know.'*

The MS specialist nurse has provided advice and assisted through difficult times.

*'He is good. He is busy...He gives me advice and things. I can ask him questions about new treatment. He doesn't always have the answers but sometimes no one knows... Always there for me and a shoulder to cry on. He has seen me through some really rough times.'*

Although Participant C's care has been good, she has not received much assistance regarding maintaining employment. Participant C has not had any assistance from an occupational health professional. Additionally, most of the health professionals she sees have not provided advice about employment and work. Instead they have let her 'get on with it.' In terms of additional support and interventions, Participant C has not focused too much on it, and does not really know what else is out there.

*'I suppose because I am really still quite fit and well, I have not really looked around for anything. Because I am not in a position where I am not immobile or anything, I haven't had to look at that yet.'*

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