



multiple sclerosis
international federation

Multiple sclerosis at work: an employer's perspective

May 2011

Foreword

Given the continuing economic challenges around the world, this global survey of the perspectives of employers in relation to MS and work is highly timely.

The importance of work is well documented, as are the challenges that people affected by MS can face in remaining in employment. However research, including the survey carried out by MSIF in 2010, has shown that just a few simple changes can support people with MS to remain in work.

This survey, which includes the responses of more than 3,500 people from over 100 countries, helps to reveal the extent to which employers are helping to meet the needs of people with MS.

The results are mixed. The majority of respondents said that there was anti-discrimination legislation in place, but only half of workplaces were fully accessible and less than a quarter had a quiet place for employees. Worryingly, less than one-fifth of respondents felt that someone developing a visual impairment would be able to continue in their role. With an estimated one-third of people with MS experiencing problems with their vision, this could potentially affect almost 700,000 people around the world.

It is vital that organisations such as MSIF, supported by their member societies around the world, continue to raise awareness of the difficulties for people with MS in remaining in employment and the changes that employers and governments can make to support them. For example the MS Society in the UK was delighted to have been able to work with the UK government and a number of other charities to develop the *Your work health* website (www.yourworkhealth.com), which provides helpful information to both employers and employees on their rights, obligations and how they can help.

I welcome this report, and the focus of World MS Day on work, and hope that we can continue to work together to address the issues raised.

A handwritten signature in black ink, appearing to read 'Ed Holloway', with a long, sweeping diagonal stroke extending from the bottom of the signature.

Ed Holloway
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|-----------------------|---|
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1.0 Introduction

Work is a fundamental aspect of our lives. It provides not only a salary, but a sense of self worth, an opportunity to lead an independent life, and to be a fully integrated member of society.

To mark World MS Day 2010, MSIF published the results of a study commissioned into the global economic impact of MS, which highlighted loss of employment, or early retirement, as the single largest factor contributing to the total cost of MS.

These findings were complemented by a global online survey of people with, and affected by, MS. The survey showed that simple, low-cost changes, such as flexible working hours or conditions, seated work and routine or predictable workload, could enable people with MS, or people caring for a person with MS, to stay in work for longer.

MSIF wanted to learn how widely these kinds of policies and practices exist in workplaces around the world, and how many employers and staff believe that their place of work is 'MS friendly'. MSIF therefore conducted a second international survey, the results of which are presented here.

2.0 Methodology

The survey was designed online using SurveyMonkey (www.surveymonkey.com) and was available in nine languages: English, Spanish, German, French, Portuguese, Russian, Finnish, Arabic and Romanian. It was promoted on the World MS Day website, www.worldmsday.org, and through MSIF's and our member societies' mailings, websites and newsletters.

All results were downloaded into an Excel spreadsheet for the final analysis of data. The survey numbers were obtained by adding together all the results of the surveys in the nine languages. The number of people who completed each language survey is as follows: English (2,432), German (471), Spanish (213), French (198), Portuguese (72), Arabic (42), Russian (42), Romanian (26) and Finnish (10). In the description of each question, N is the total number of people who answered that question.

3.0 Results

3.1 *Location of respondents*

By mid April 2011, 3,506 people from 107 countries had taken the survey (with 58% completion rate).

The USA had the highest representation with 689 people (22.2%), followed by Norway (11.1%), Canada (10.9%), Germany (8.5%), Australia (6.7%), South Africa (4.2%), United Kingdom (3.8%), Switzerland (3.7%), Belgium (2.7%), Spain (2.4%), Portugal (1.7%) and Argentina (1.6%). Each of the other countries accounted for less than 1% of responses.

3.2 Company details

Respondents were asked to indicate the type of business performed by their company, and the number of employees. They were also asked to indicate whether their company operates locally, nationally or internationally.

Figure 1 shows a wide distribution of business types; health and medicine (533 companies; 17.2%), education (11.9%) and public sector (8.2%) being the most common types. (N=3,463)

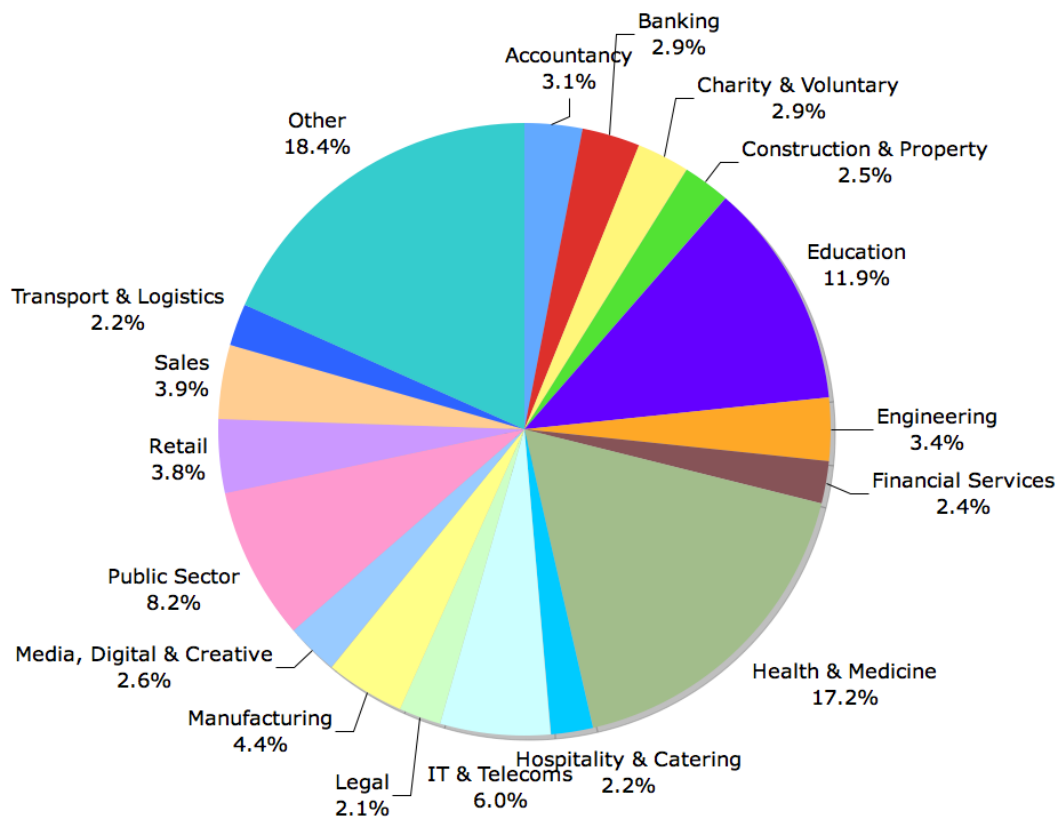


Figure 1: Type of business

Large companies predominated. 1,277 companies (36.4%) employ more than 500 people. (N=3,505)

Nearly half the companies operate on a local basis (1,735 companies, 49.6%), with the rest being fairly evenly divided between national (28.2%) and international (22.3%) operations. (N=3,505)

3.3 *Employment practices*

3.3.1 Legislation

Figure 2 shows the extent of international legislation protecting current or potential employees against discrimination in employment (in both the hiring and retention phases). 2,347 respondents (71%) indicated that such legislation exists in their country, with 23.1% being unsure. (N=3,306)

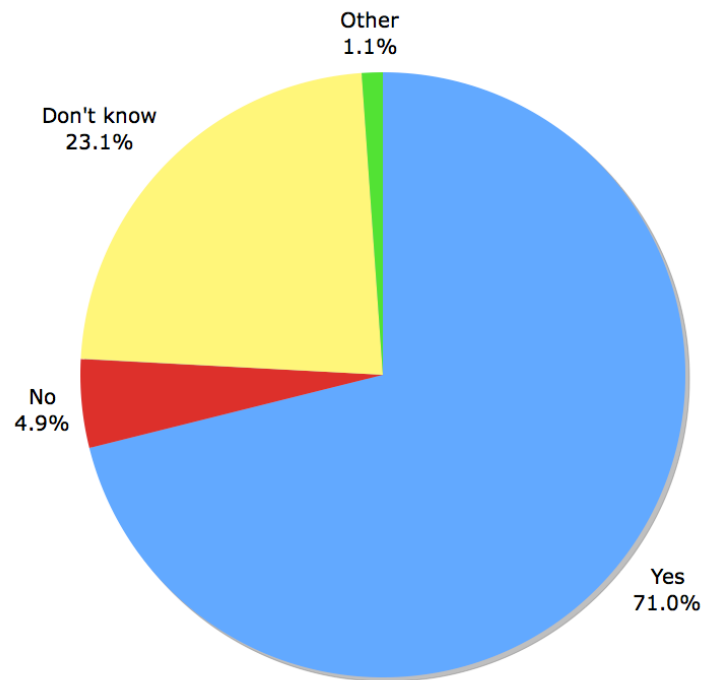


Figure 2: Anti-discrimination legislation

3.3.2 Working environment

Respondents were asked about the facilities available at their place of work.

The survey found a fairly even split between workplaces that are fully wheelchair accessible (48.7%) and those that are not (47%), with 4.3% of respondents unsure. (N=2,092)

Figure 3 (overleaf) shows that a large majority of respondents (1,478; 70.7%) are employed in workplaces without access to an employee lounge or quiet space where employees can rest or sleep during the day. (N=2,092)

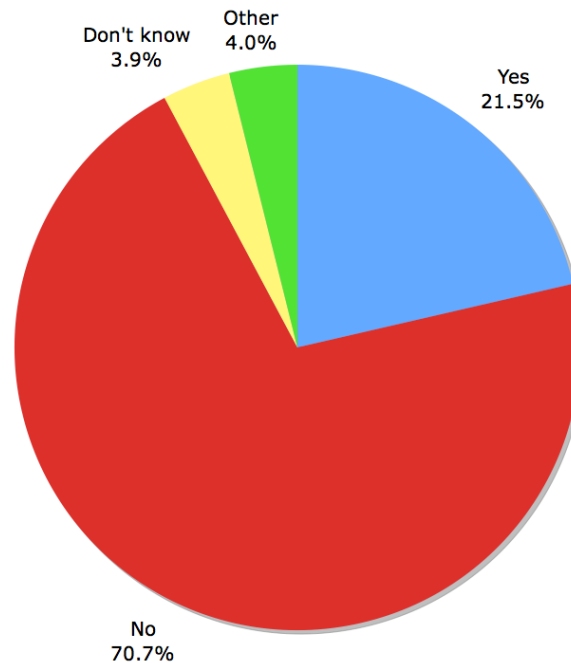


Figure 3: Availability of quiet space for employees

3.3.3 Company policies

Respondents were questioned about the policies and attitudes of their business surrounding the welfare of their employees.

- There was a fairly even split between yes and no responses to the question: Does your company have a specific policy on 'diversity' that includes disability or a policy related specifically to disability in the workplace that recognises the contribution that people with disabilities make to company innovation and culture? 38.1% answered Yes, 38.9% No, and 22.9% did not know. (N=2,092)
- Survey participants were asked whether they believed their company actively encourages employees to progress within the company into higher roles, and whether adequate training is provided. Just over half of respondents (53.3%) considered that this encouragement and training is provided. However, over a third (34.9%) thought that this is not the case with their company. The remainder did not know. (N=2,673)
- They were also asked whether their company's line managers were encouraged to take on a personal guidance or care role for their team. Nearly half of respondents (49.8%) believed that this encouragement is given, with a little over a quarter (27.5%) believing their company does not do so, and almost a quarter (22.7%) unsure. (N=2,673)
- Respondents were then asked whether their company encourages employees to support one another in the workplace, with two thirds (66.9%) believing that their company does so, just under a quarter believing it does not (23.5%). 9.5% were unsure. (N=2,673)

Responses were fairly evenly split between participants whose companies allowed flexible working hours or working from home options, (1,286 responses; 48.8%), and those that did not (46.5%). (N=2,634)

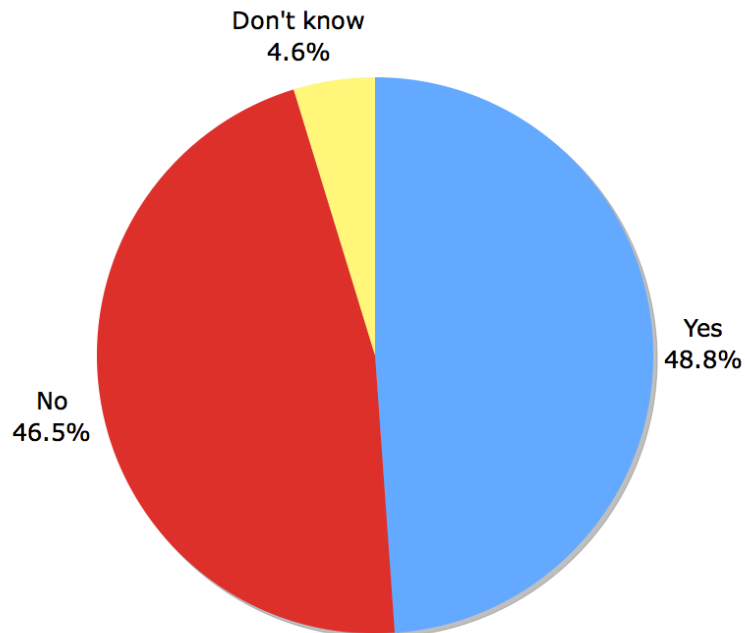


Figure 4: Flexible hours/working from home options

Figure 5 shows the responses when participants were asked whether employees are entitled to short-term sick leave when they fall ill. More than three quarters answered yes (2,043 responses). (N=2,634.)

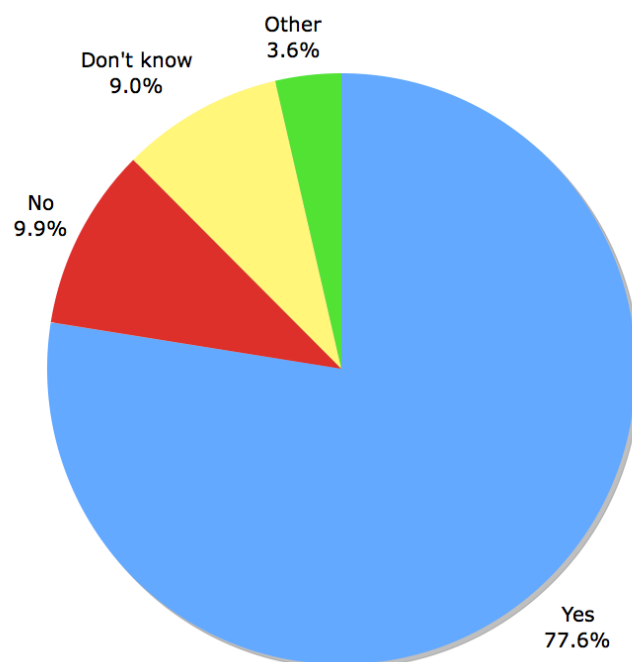


Figure 5: Short-term sick leave entitlement

Participants were then asked whether short-term sick leave would be paid leave. Figure 6 shows that more than three quarters answered yes (1,564 responses). (N=2,042)

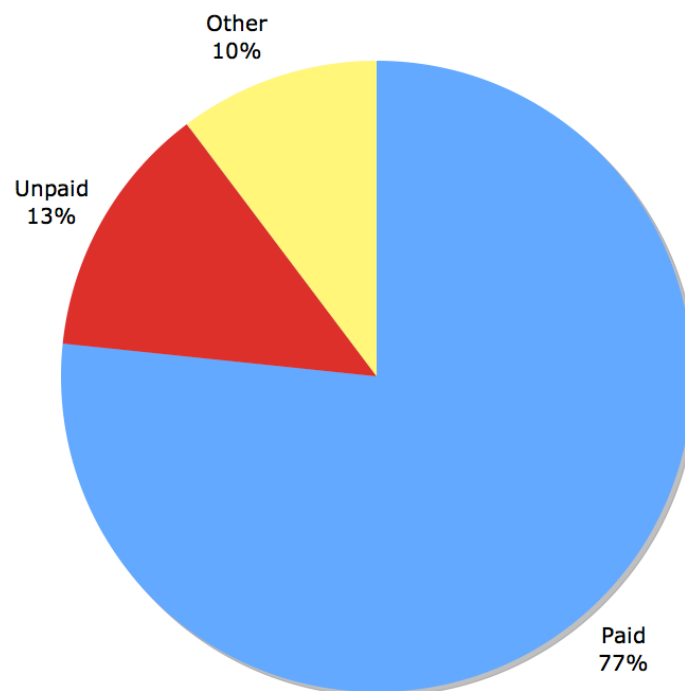


Figure 6: Short-term sick leave – paid or unpaid?

Figure 7 shows the responses when participants were asked whether employees are entitled to long-term sick leave when they fall ill. The proportion of yes responses in this case was reduced to 64.5% (1,686 responses). (N=2,612)

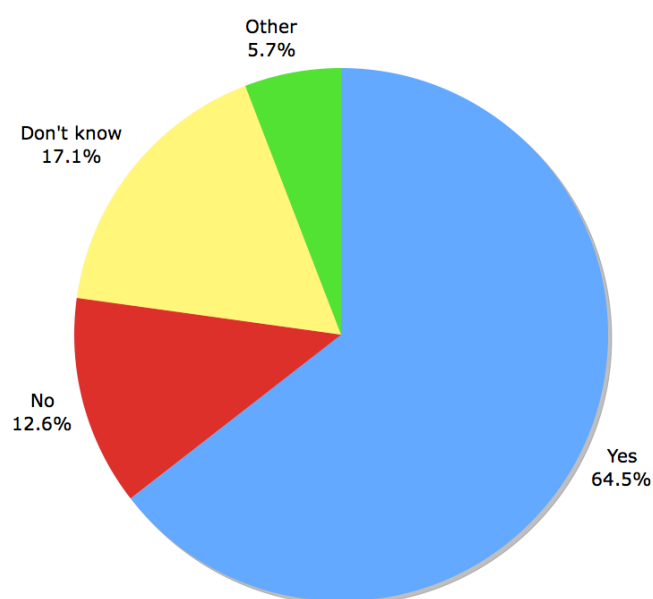


Figure 7: Long-term sick leave entitlement

Participants were asked whether long-term sick leave would be paid leave. Figure 8 shows that just over half answered yes (1,050 responses). (N=1,707)

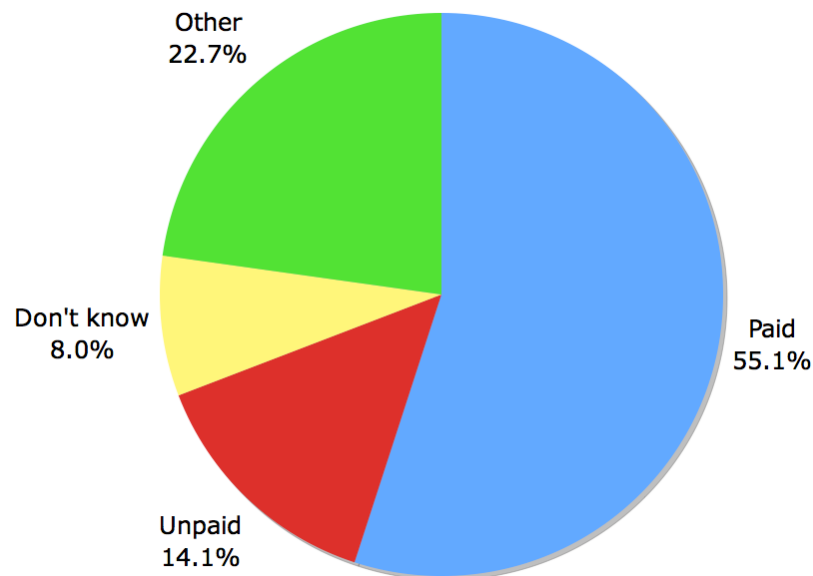


Figure 8: Long-term sick leave – paid or unpaid?

59.9% of respondents (1,254) feel that those living with chronic and fluctuating conditions such as MS would be encouraged to remain with the company, in the same or another role, after disclosure of their condition (see Figure 9). (N=2,092)

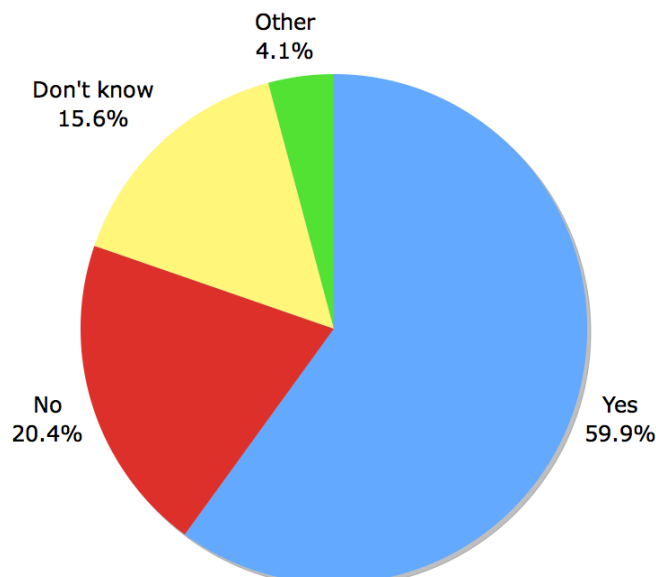


Figure 9: Those living with chronic and fluctuating conditions such as MS would be encouraged to remain with the company

Figure 10 shows that 53.3% of respondents (1,114) believe that an employee developing a visual impairment would not be able to continue in his/her role at the company. Only 18.6% believe that such an employee would be able to continue in his/her role. (N=2,092)

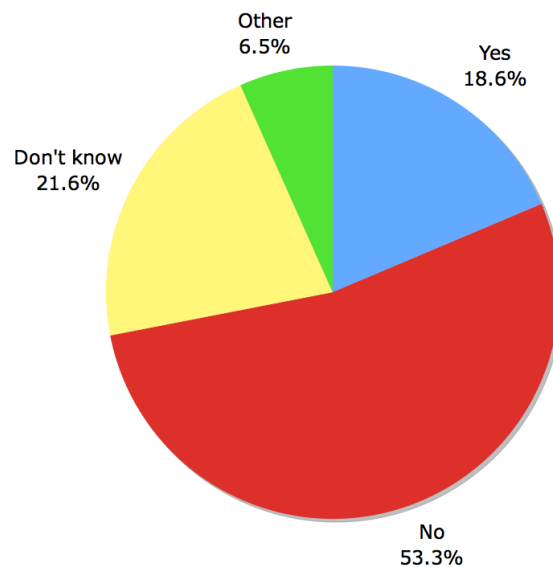


Figure 10: Would an employee who became visually impaired be able to continue in his/her role?

Respondents were asked if and how their company would expect a newly diagnosed employee to disclose their new health status. 38% (845) replied that their company would not expect an employee to disclose their health status; 44.1% expected the change of health status to be disclosed in person (see Figure 11). (N=2,092)

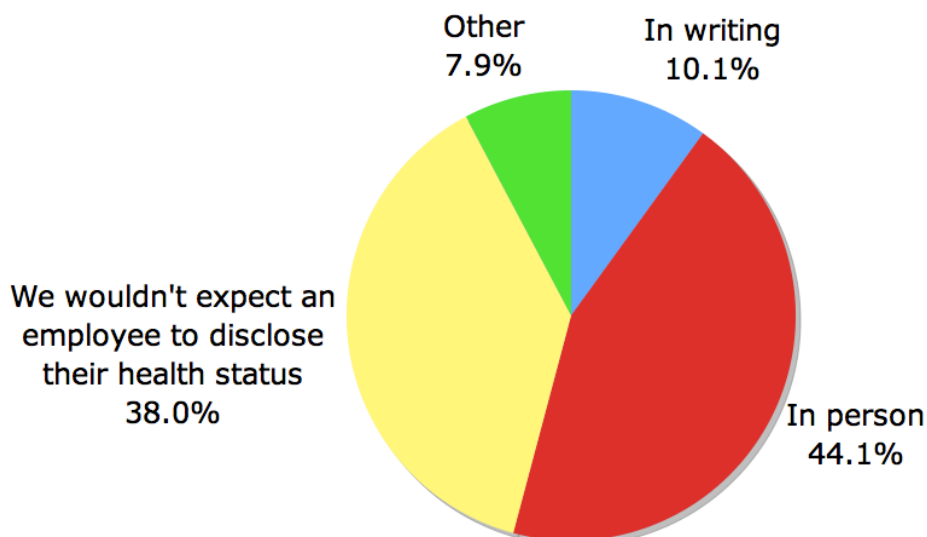


Figure 11: How would your company expect a newly diagnosed employee to disclose their new health status?

4.0 Access to healthcare

Respondents were asked about the provision of health insurance and medical services for their employees.

Figure 12 shows that just over a third of participants (930) said that their company provides employees with a health insurance policy that includes treatment. Almost as many said they were covered by a national health service. Just under a fifth of the respondents indicated that their company did not provide health insurance and that there was no national health service. (N=2,563)

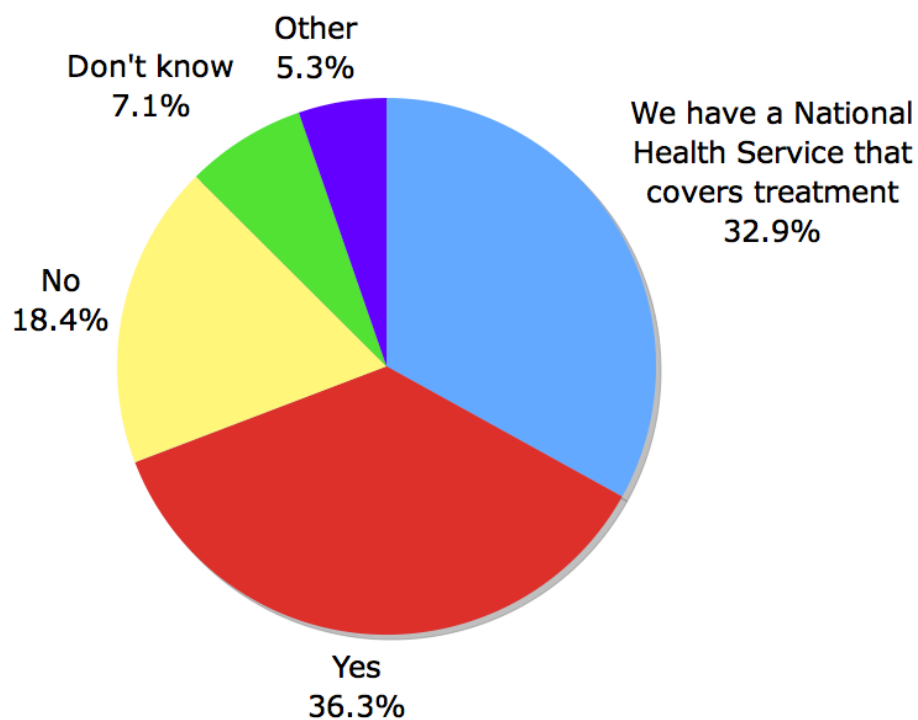


Figure 12: Are employees covered by a health insurance policy that includes treatment?

For those covered by a health insurance policy, figure 13 shows whether the cost is borne by the employer, the employee or both (64.7%; 558 respondents). (N=862)

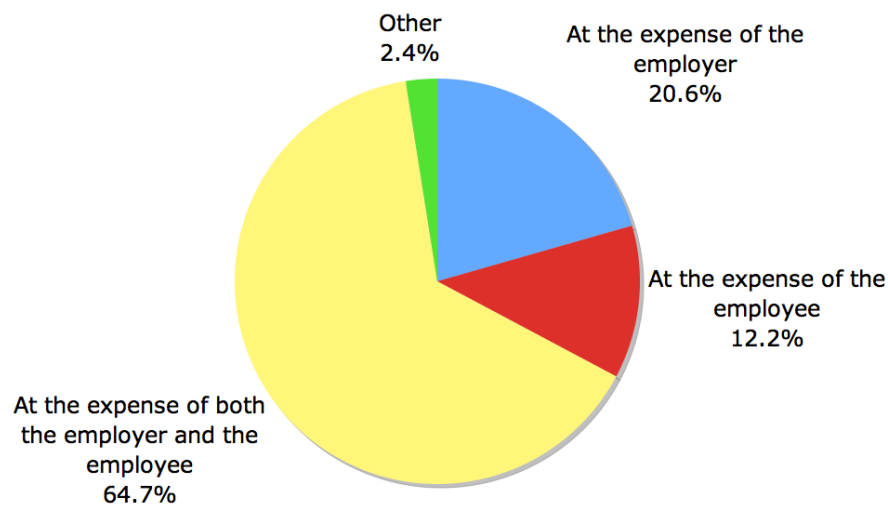


Figure 13: Who bears the cost of health insurance?

Respondents were asked whether employees have access to a counsellor, psychologist or other mental health professional through the company. Figure 14 shows that 33.6% of respondents' (836) companies provide this access, with 37.3% not doing so. (N=2,490)

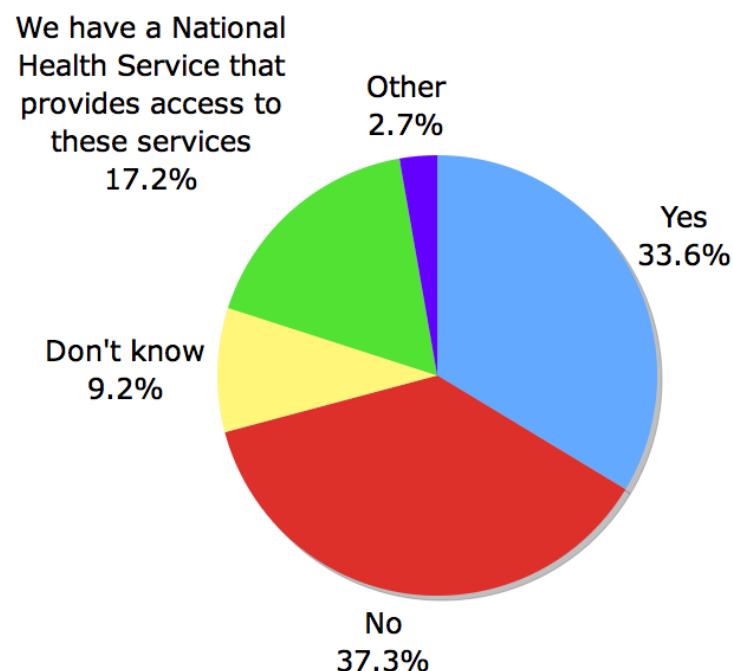


Figure 14: Do employees have access to a counsellor, psychologist, or other mental health professional through the company?

5.0 Accommodation of chronic conditions

The survey included two questions about employers' accommodation of employees with MS and other chronic conditions. The first question asked what accommodation the respondent would expect an employer to make for an employee diagnosed with MS; the second asked what accommodation had actually been made for disabled employees, or those living with a chronic fluctuating illness.

Rather than supplying respondents with a limited number of options, the questions were open-ended and allowed participants to enter their answers as text. These answers have been analysed, and categorised: the same set of categories has been used for both questions.

Figure 15 shows the accommodations that survey respondents suggested employers should make for employees with MS. The most suggested option was to allow for flexible/shorter hours (310 respondents; 19%), with meeting individual requirements (12.3%), building modification (12 %) and workspace adaptation (10%) also popular suggestions. (N=1,253)

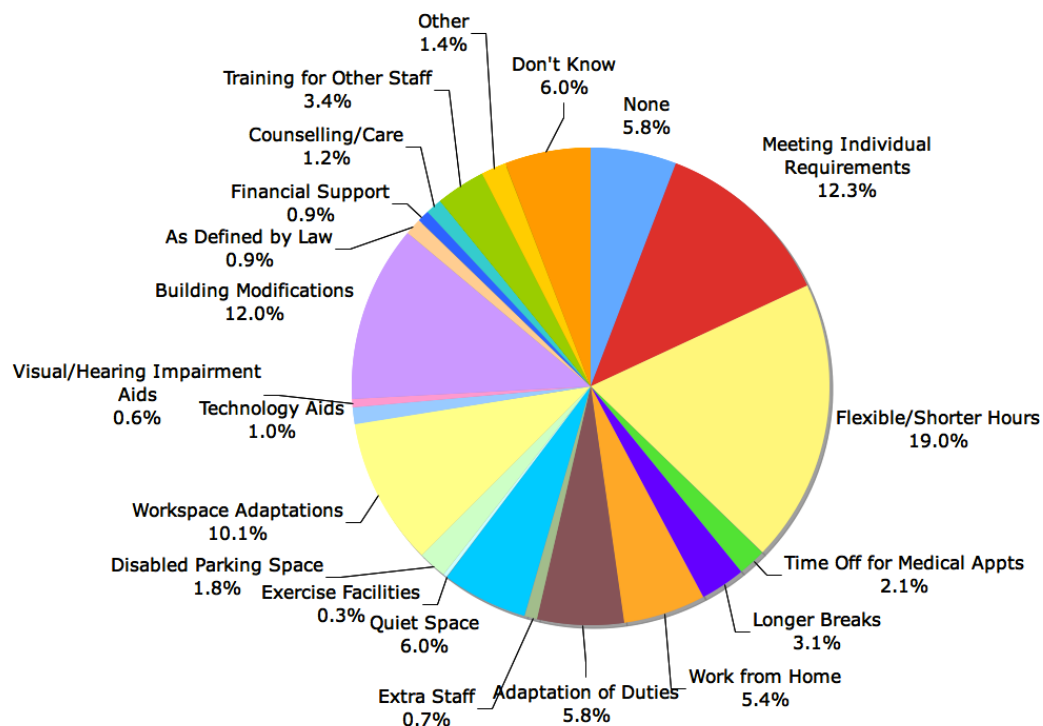


Figure 15: What kind of accommodations would you expect employers to make for an employee who is diagnosed with MS? ¹

¹ Most category names should be self-explanatory, but some may need clarification:

- **Meeting individual requirements** – the employer has worked (or is expected to work) with the affected employee to meet their particular needs
- **Flexible/shorter hours** – includes allowing short- and long-term sick leave
- **Quiet space** – a separate room for resting or sleeping during work hours
- **Building modifications** – wheelchair ramps, bathroom modifications, air-conditioning, etc
- **Workspace adaptations** – tables at wheelchair height, special chairs, moving the employee's work area to the ground floor, etc
- **As defined by law** – the employer has made (or is expected to make) the adjustments required by local laws, but has not exceeded these requirements
- **Training for other staff** – training in understanding MS (or other chronic condition).

Figure 16 shows the accommodations that employers have actually made in the past for employees who are disabled or living with a chronic fluctuating illness. 'None' was easily the most frequent response (373 responses; 29.6%), with flexible/shorter hours again being frequently cited (14.4%). (N=1,224)

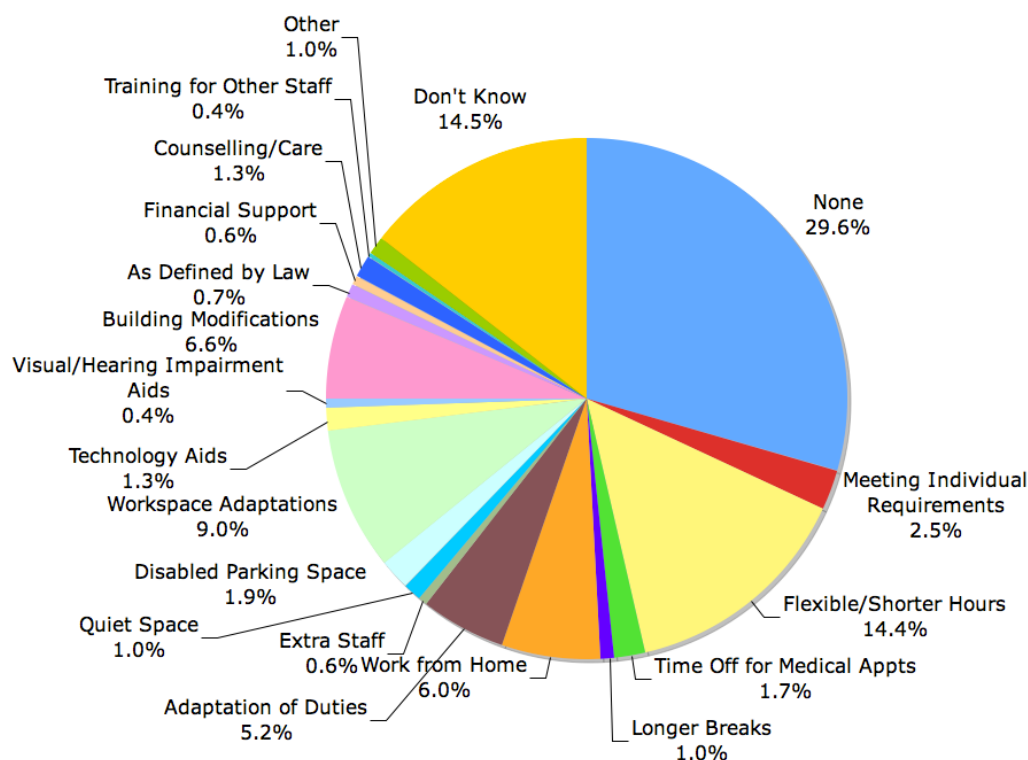


Figure 16: Accommodations already made for employees who are disabled or living with a chronic fluctuating illness

6.0 Limitations

The survey was promoted through the World MS Day website and Facebook page and also advertised through MSIF member societies. Respondents were thus a self-selecting sample. The fact that it was an internet-based survey could also influence the sample population.

The survey is also mainly represented by English-language speakers, despite being conducted in nine languages. There are likely to be both similarities and differences between individual countries, and between large and small countries, that are not discussed in this report.

A substantial proportion of people taking the survey were in non-management positions (1,125 people; 36.2%), and 24.5% were self-employed or in other

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- **Counselling/care** – includes specialist training for staff in how to care for the person with MS.
 - **Extra staff** – to help the person with MS with his/her duties, or with mobility, etc
 - **Financial support** – medical insurance, transport costs, pension, etc

undefined positions. There may be a difference in perspective from the rest of the respondents who were in management positions.

Lastly, minor discrepancies in the construction of the Arabic and French versions of the survey invalidated some of the questions in relation to figures 1 and 11. We therefore omitted the relevant language replies to those questions only.

7.0 Conclusions

A striking result of the survey is that the majority of respondents (71%) believed that legislation was in place to prevent discrimination against people with MS and other diseases in both the hiring and retention phases of employment. However answers to subsequent questions suggest that in many cases this legislation is limited in scope, is not enforced, or that the respondents were unaware of the policies of their companies.

Access and accommodations

Less than half (48%) of respondents said that their office, or place of work was wheelchair accessible. The 2010 survey found that respondents felt that an accessible workplace (15%) and an elevator in the office (17%) were important facilities that would enable people to stay in work. More than 70% of respondents to the same survey said that difficulty walking and moving had prevented them from staying in work. Since people with MS face varying levels of disability, accessibility clearly is a significant barrier to work in many cases. Moving workspace to the ground floor, close to toilets and installing handrails may assist with mobility issues.

Raising desk heights to accommodate mobility equipment, investing in computer software for visual impairments and adaptive equipment for impaired hand function are all changes that may enable a person with MS to take on, or stay in work in an office environment.

Rest

More than two thirds of respondents said that they did not have a place to rest (70.7%). While just 10% of respondents to the 2010 survey said that a place to rest was an important factor in enabling them to stay in work, more than 80% of respondents to the same survey said that fatigue had prevented them from remaining in employment. Providing a place to rest, and ensuring that the office culture allows staff to use it, could be an important change.

Support from managers and peers

The perceived level of support for the development and care of employees were similar. Around 50% of respondents felt that their company actively encouraged progression with the company and the same number felt that managers took on a personal care role for employees within their team. Support, both from managers and peers, was shown to be an important factor in enabling a person with MS to stay in work in the 2010 survey. A lack of

support may result in feelings of isolation, misunderstanding and stress for a person with MS. It is important that managers understand the changeable nature of chronic fluctuating diseases like MS, and that the channels of communication remain open, in particular to assess what flexible support would make it possible to stay in employment. Disturbingly, one fifth of respondents said that someone with MS would not be encouraged to stay in work.

Increased awareness and understanding of MS, and of the workplace requirements and considerations of people with MS, should remove many of the misconceptions employers have about MS. Scheduling and offering in-service training on MS, open to everyone but especially targeted at hiring officials and managers/supervisors to attend, could prove very helpful. This will hopefully lead to a more supportive and open environment where employees might feel more comfortable disclosing their status and requesting accommodations, and perceiving that they are supported in staying and advancing with their company.

Access to healthcare

Access to medication was listed as being a significant factor in enabling a person with MS to stay in work in the 2010 survey. The 2011 survey found that around 18% had no access to treatment through employer funded (partly or fully) insurance, or through a national health system. MS symptoms can be managed through a number of therapies but for many people with MS these therapies are unaffordable.

It is in the interest of employers and governments to address the large gap in healthcare both for the health and well-being of individual people with MS and their families and carers, and equally to maximise the contribution that people with MS make to society as a whole.

Flexible office hours – working from home

Implementing a flexible working policy may be cost free and could even reduce costs. In many cases it will enable a person with MS the freedom that they need to manage their workload and their symptoms successfully. Almost 40% of respondents to the 2010 survey said that flexible hours would have enabled them to stay in work, however almost 50% of respondents to the 2011 survey said that flexible working is not available at their places of work. A flexible working policy would ensure that workplaces are accessible not only to people with MS but also to those with other chronic fluctuating diseases, people with children, and people with other personal situations which might make continued attendance at a specified place of work, between specified hours, difficult.

8.0 Recommendations

Employers and governments can make a huge difference for people with MS and help them stay in work or take up new employment. We call on employers and governments to:

Employers:

- Implement measures such as flexitime, working from home, and child-care provision, and ensure that buildings and facilities, including computer equipment, are accessible to people with MS and other disabilities;
- Recognise the role that people with MS and other disabilities have in contributing to a diverse workplace through diversity or inclusion policies; include disability in diversity-related recruitment policies;
- Ensure that company culture is open to making accommodations for people with disabilities in the workplace.
- Offer in-service training on MS and other conditions to all staff but especially managers/supervisors;
- Contact national MS or disability organisations or MSIF for the best advice in relation to implementing measures that will enable people with MS to work;
- Become familiar with the legal rights of people with disabilities in the workplace in your country, and the company's legal responsibility as an employer;
- Pledge to make one significant change in 2011 to make it easier for people with MS and other disabilities to stay in employment.

Governments:

- Ratify the UN Convention on the Rights of Persons with Disabilities;
- Ensure that national legislation is in place to provide support for people with MS and other disabilities and ensure the absence of discrimination;
- Provide systematic guidance and advice to employers and companies on how to support people with MS and other disabilities at work and on the appropriate measures to implement the legislation;
- Create mechanisms to ensure implementation of this legislation, such as regular reviews and inspection regimes, and /or an appropriate

agency with powers to investigate appeals from employees when they feel their companies fail to respect the disability legislation.

- Ensure provision of vocational, work related rehabilitation, coordinated with clinical care and health services;
- Ensure entitlement to disability-related leave, such as for therapy or rehabilitation activities.