



multiple sclerosis  
international federation

# **MSIF survey on Employment and MS**

**April 2010**

## Foreword

I have a clear memory of seeing my father in his office in Amsterdam on his last day at work. He had finally decided that the fatigue caused by his MS meant he could not go on working. I watched him struggling with decisions about what to throw out, what to keep and what to give away. Saying goodbye to his colleagues and to what had been such a huge part of his life. It was heart-breaking to see him deal with that.

That was more than thirty years ago. But from talking to people with MS today, it is clear that some things have not changed. Despite many advances, MS still has profound implications for employment - while the ability to work is as crucial as ever - for income, for social contact and for quality of life. Meanwhile, MSIF's literature study of the economic impact of MS shows that it is also the single most important factor in the global economic burden of MS.

Some things have changed. New treatments have been developed, and there is real hope of new research breakthroughs. In many countries legal protection against discrimination has improved, along with attitudes.

But much remains to be done. This first ever global survey about employment and MS confirms some findings from earlier studies and opens up new areas.

We hope that governments, employers, medical professionals and MS Societies around the world will learn from this survey to further develop the legislation, advice services and other measures to defend people's right to work and help people with MS stay in work.

Peer Baneke  
CEO  
MS International Federation

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# World MS Day Employment and MS survey

## 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. A study commissioned by MSIF into the global economic impact of MS highlighted the loss of employment / early retirement as the single largest cost factor in the total cost of MS. This represents not only a direct cost in terms of loss of earnings but indirect costs in terms of quality of life, and affects not only the person with MS and their family but also society as a whole. In order to gain a global perspective of the impact of MS on employment and to raise awareness of work-related issues faced by people with MS, we designed a global online survey on 'employment and MS'. The survey was linked to the World MS Day website - [www.worldmsday.org](http://www.worldmsday.org).

## 2.0 Methodology

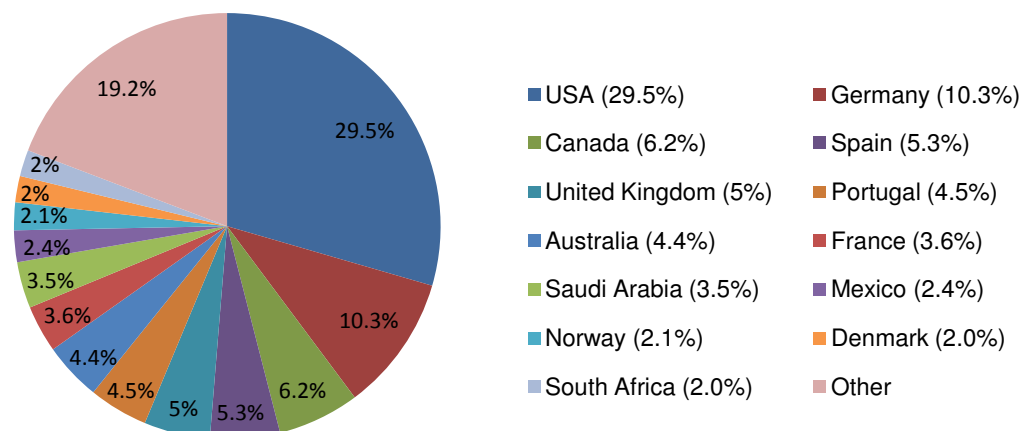
The survey was designed online using survey monkey ([www.surveymonkey.com](http://www.surveymonkey.com)) and was available in ten languages: English, Arabic, Chinese, French, German, Hindi, Indonesian, Portuguese, Russian and Spanish. All results were downloaded into an Excel spreadsheet for the final analysis of data. The survey numbers were obtained by adding together all the results of the surveys in the ten languages. The number of people who completed each language survey is as follows: English (5,035), German (732), Spanish (653), Portuguese (355), Arabic (309), French (250), Russian (97), Chinese (45), Hindi (12) and Indonesian (11). N is the total number of people who answered each question.

## 3.0 Results

### 3.1 Demographics

By mid March, the survey was taken by 8,681 people (with 86% completion rate) from 125 countries. 73% (6,351) of the respondents were female, 27% male and 87% (7,524) had MS. Of the 13% of respondents who didn't have MS, 90% (1,120) had a partner, family member or friend with MS and 32% of these were carers of a person with MS.

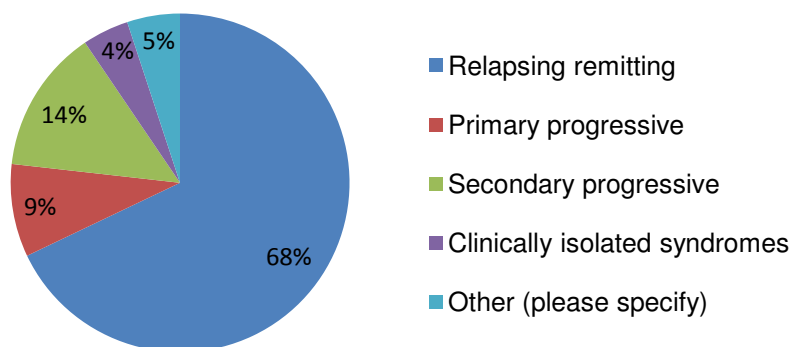
Figure 1 below shows the distribution of survey participants by country with all countries representing more than 1% of the total number of respondents listed. USA had the highest representation with 2,565 people (29.5%), followed by Germany (10.3%) and Canada (6.2%).



**Figure 1: Worldwide distribution of survey respondents**

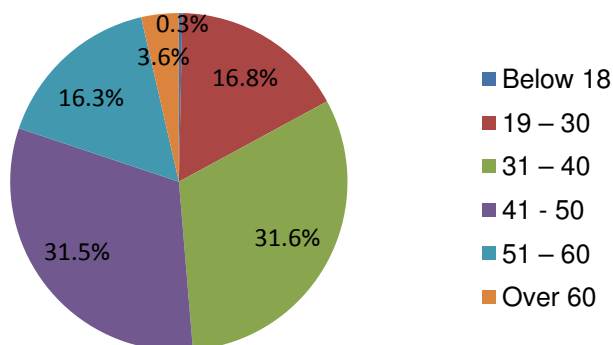
### 3.2 People with MS

People with MS taking the survey were asked to list their type of MS, age group and how long they have been diagnosed with MS. As shown in Figure 2, most respondents were in the relapsing-remitting category (68%).



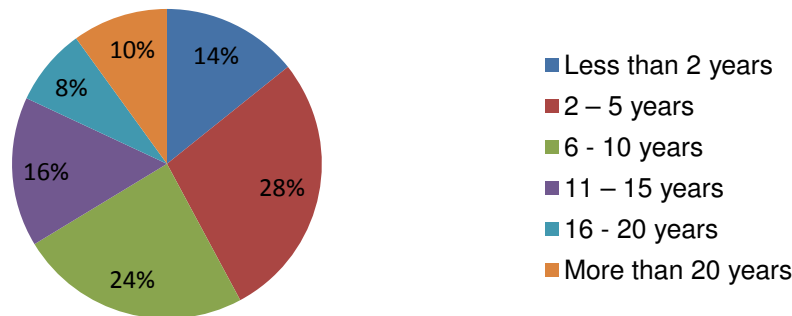
**Figure 2: Distribution of respondents by types of MS**

Figure 3 below shows the distribution of respondents by age group. The 31-40 (31.6%) and 41-50 (31.5%) age groups were most represented with 0.3% representing the paediatric MS population.



**Figure 3: Distribution of respondents by age groups**

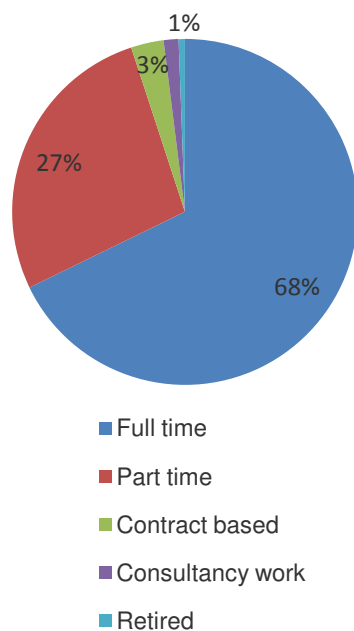
As shown in Figure 4 below, a majority of the respondents had been diagnosed with MS for less than 10 years (less than 2 years – 14%, 2-5 years – 28%, 6-10 years – 24%).



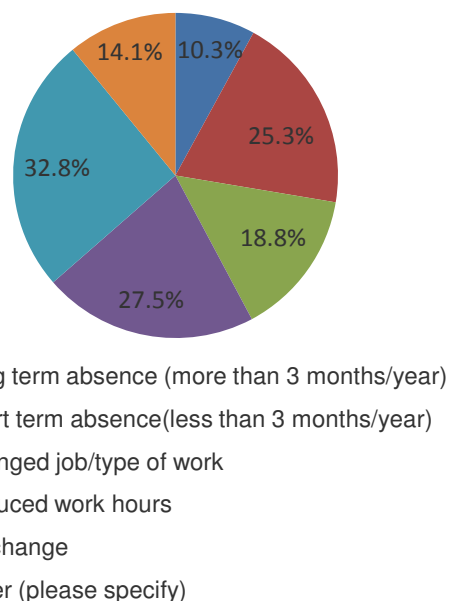
**Figure 4: Distribution of respondents by number of years diagnosed with MS**

### 3.3 People with MS in employment

59% (4,336) of people with MS were employed (N = 7,290). As shown in Figure 5, the majority (68%) were in full-time employment, 27% working part-time, 3% in contract based employment and 1% were in consultancy work. A further 1% had recently retired. When questioned on how having MS had affected their work, Figure 6 shows that 27% had to reduce working hours, 25% had taken short-term leave (less than 3 months in a year), a further 10% had been on long-term leave. 19% had changed jobs or type of work. Only 33% reported no change, indicating that having MS had, at some stage, impacted on the work of a majority (67%) of respondents (N = 3,917).



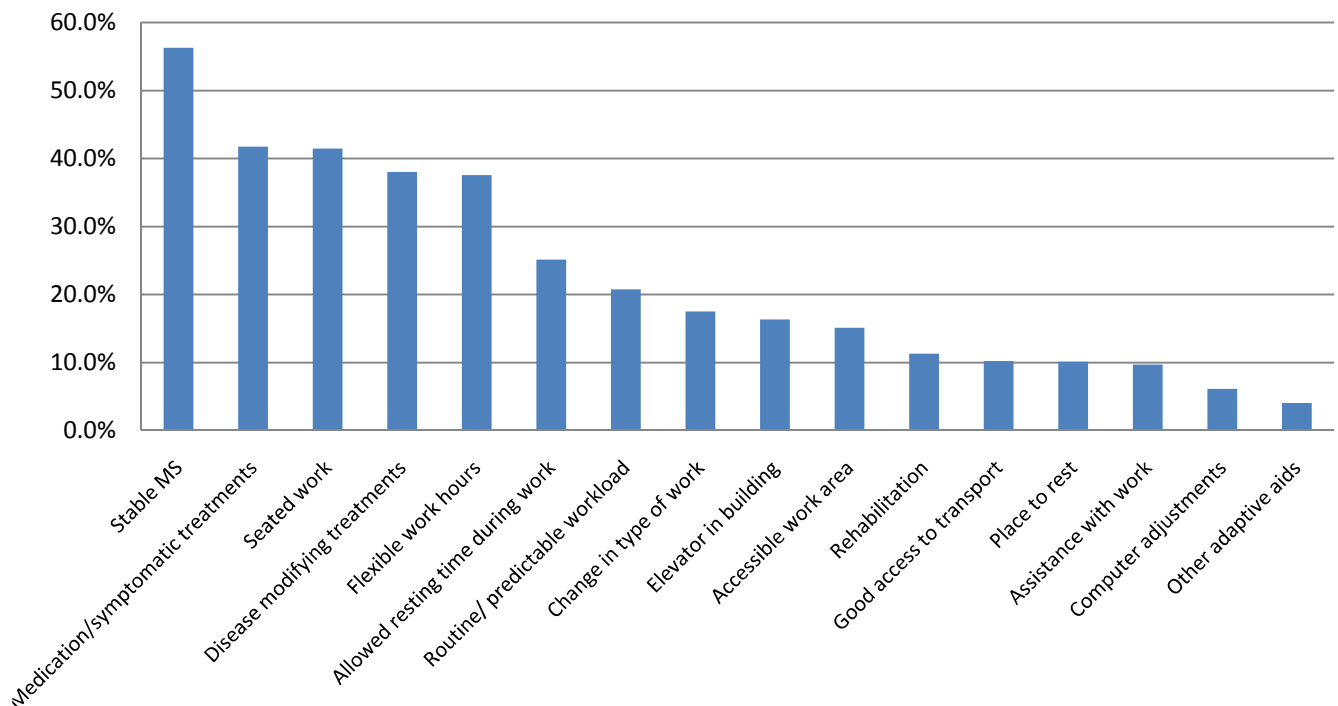
**Figure 5: Type of work**



**Figure 6: How MS has affected work**

### 3.3.1 Factors that enabled people with MS to remain in employment

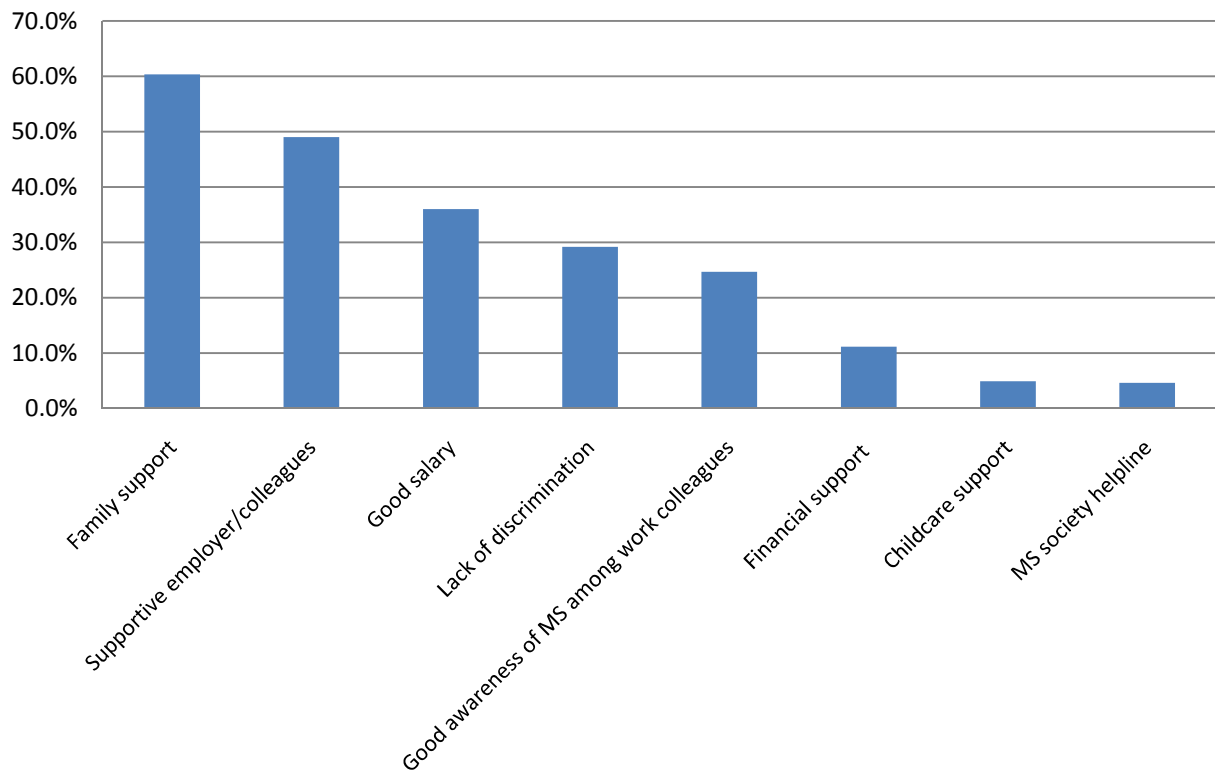
Figure 7 below shows that stable MS (56.3%), medication/symptomatic treatments (41.8%), seated work (41.5%), disease modifying treatments (38%) and flexible work hours (37.6%) were listed as the most important MS-related factors enabling people with MS (who were already employed) to remain in employment. Computer adjustments (6.1%) and other adaptive aids (4%) were listed as less important (N = 3,792).



**Figure 7: MS-related factors that enabled people with MS to remain at work**



Figure 8 below shows that family support (60%) and a supportive employer and colleagues (49%) were identified as the main support-related factors enabling people with MS to remain in employment while childcare support (4.9%), an MS society helpline (4.6%) and financial support (11.2%) were listed as lower priority (N = 3,679).



**Figure 8: Support-related factors that enabled people with MS to remain at work**

### 3.4 People with MS not in employment

A majority of the people with MS who were not in employment (83%), were not working due to MS (N = 2,957). 47% of these had stopped work within three years of being diagnosed with MS. Therefore almost half of the people with MS who stopped work had done so within a period of three years.

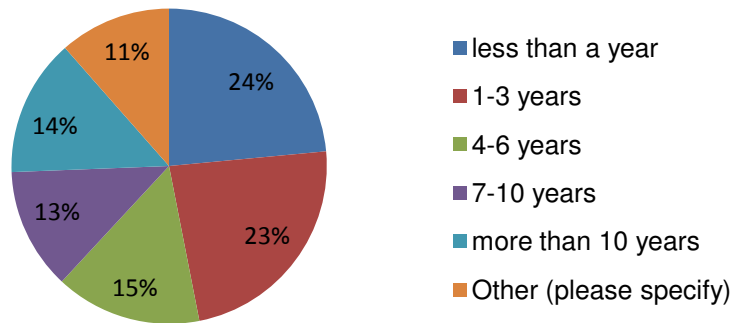


Figure 9: Number of years to stopping work after diagnosis with MS

#### 3.4.1 Data comparisons for people with MS in employment vs. not in employment

In Figure 10 we looked at the number of years people had been diagnosed with MS and compared those in employment (A) (N = 2794) with those no longer in employment (B) (N = 1795). There are striking differences between these two groups, with half those in employment having MS for five years or less compared to only 31% of those who were not in employment. Conversely, only 25% of those in employment had been diagnosed with MS for more than ten years compared to 45% of those who were not working. These figures strongly suggest that the number of years since diagnosis with MS has a significant impact on whether or not a person with MS would remain in employment. There was also a striking correlation between the types of MS between the two populations, with those in employment being predominantly in the relapsing remitting phase, while those no longer employed were more represented by the progressive phases of the disease.

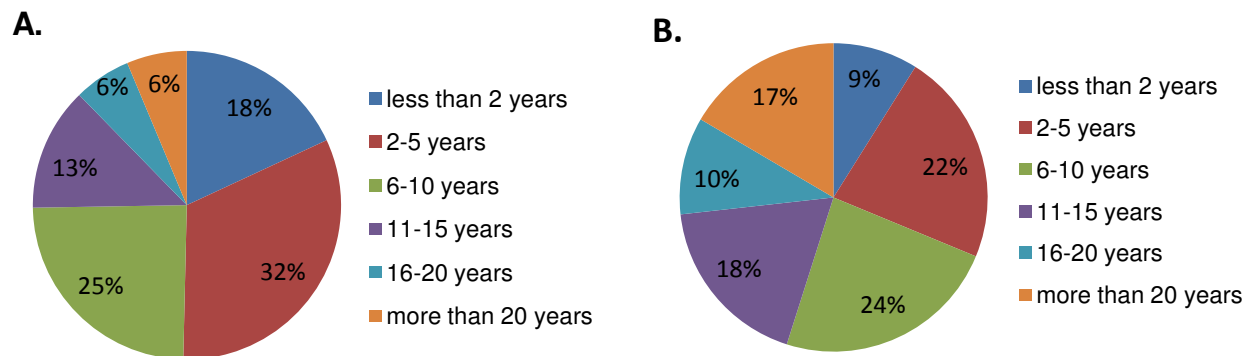


Figure 10: Distribution of respondents by number of years diagnosed with MS for those A) in employment and B) not in employment

### 3.4.2 Factors that prevented people with MS from remaining in employment

Figure 11 shows that fatigue (85%), mobility related problems (72%) and weakness (56%) were cited as the primary symptomatic factors preventing people with MS from remaining in employment, while speech impairments (13%) and tremors (17%) were listed as less important (N = 2,134).

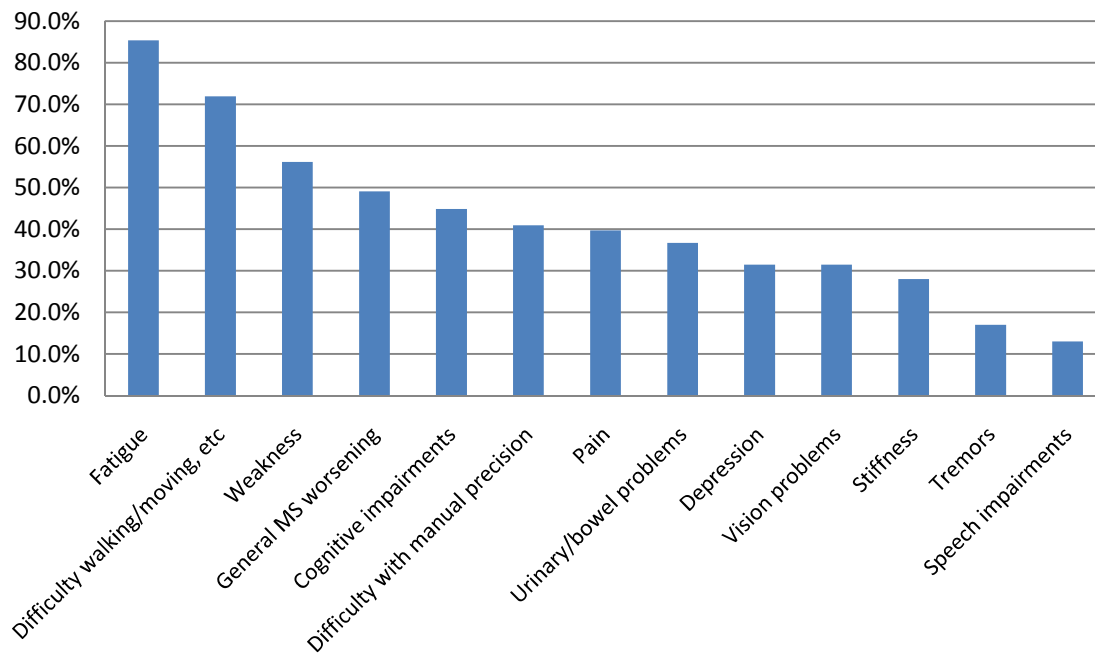
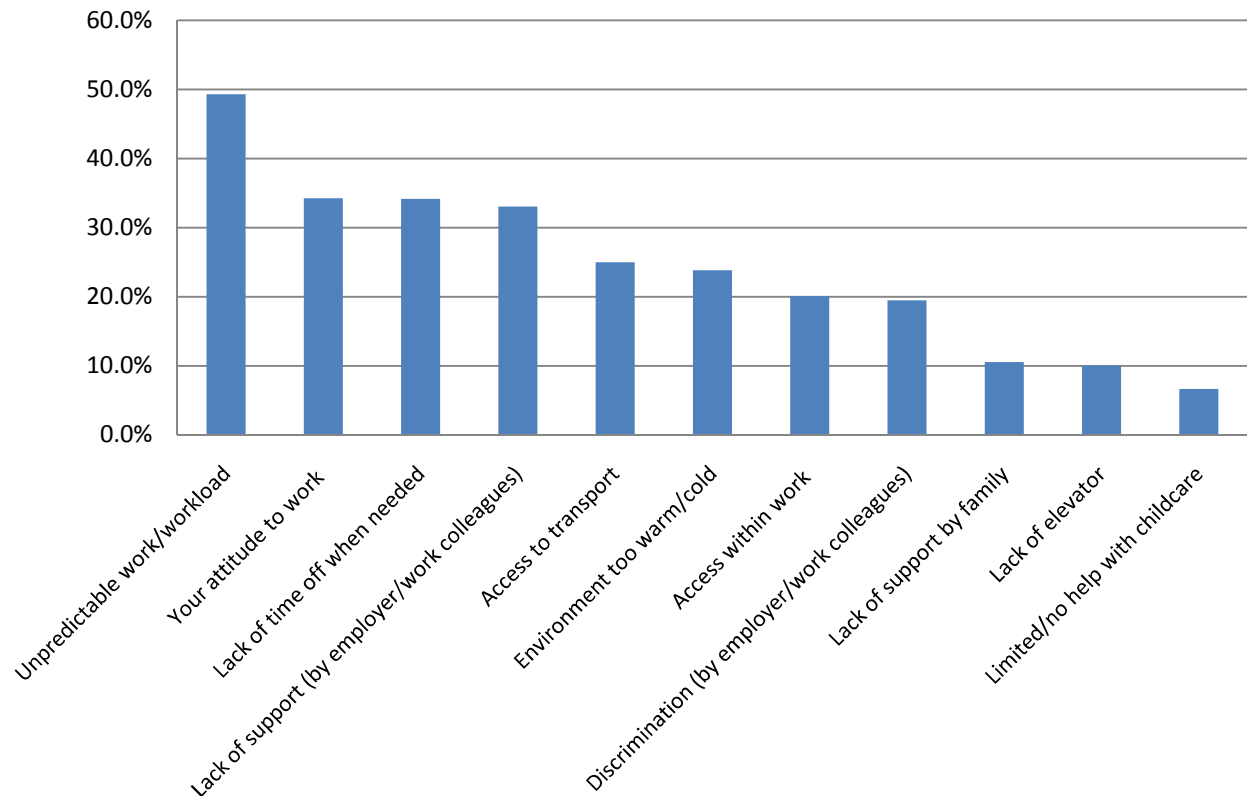


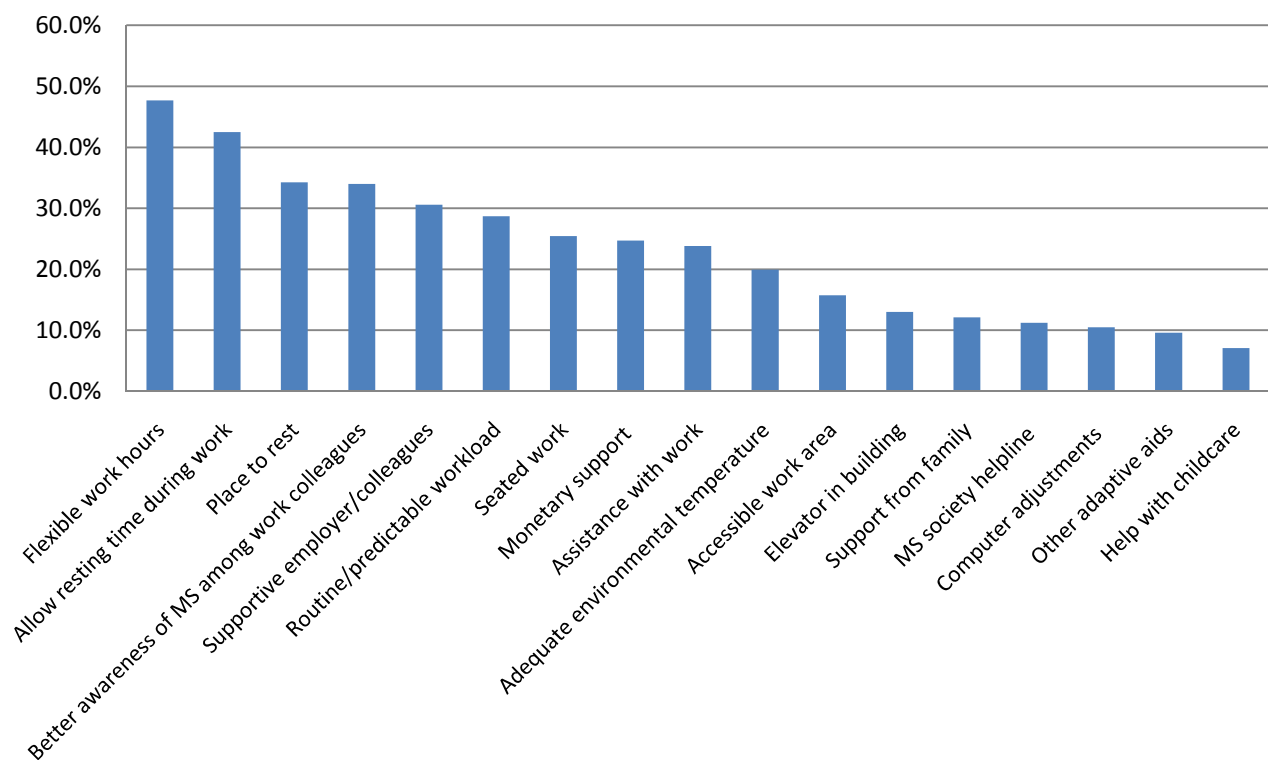
Figure 11: Symptom-related factors that prevented people with MS from remaining in employment

As shown in Figure 12, unpredictable workload (49%), attitude to work (lack of motivation/confidence, etc) (34%), lack of time off when needed (34%), and lack of support by employer / work colleagues (33%) were important 'other' (non MS-related) factors affecting the ability of people with MS (no longer in employment) to work. Limited support with childcare (6%), a lack of elevator in the building (10%) and lack of family support (11%) were listed as less important (N = 2,017). Interestingly, family support was listed as the main factor in enabling people with MS (who were in employment) to remain at work (see Figure 8).



**Figure 12: Other factors that affected the ability of people with MS to remain in employment**

As shown in Figure 13, when people with MS (who were no longer working) were asked to list the factors that would have helped them to remain in employment, flexible work hours (48%), ability to have resting time/work breaks (42%), place to rest (34%) and better awareness of MS among work colleagues (34%) were listed as high priority while computer adjustments (11%), other adaptive aids (10%) and help with childcare (7%) were listed as lower priority (N = 2,272). Interestingly, when the same question was asked of carers of people with MS, the response showed a very similar trend with flexible work hours (72%) and resting time (66%) listed as the most important factors to allow people with MS to stay in work, while computer adjustments (33%), other adaptive aids (34%), higher salary (8%) and help with childcare (6%) were listed as lower priority (N = 334).



**Figure 13: Changes that would have helped people with MS to remain at work**

### 3.5 Carers of people with MS

#### 3.5.1 Views of person with MS

Of the people with MS taking the survey (N = 6,919), 56% had a partner, family member or friend who was their carer. 78% of the carers were in employment (N = 4083). As shown in Figure 14, being a carer for someone with MS had not impacted on their work in most cases (71%), while 11% had to reduce working hours and a further 8% had changed jobs or type of work. Interestingly, 6.5% had increased their hours of work, suggesting a need for additional income to compensate for the loss of earnings of the person with MS or due to increased expenses.

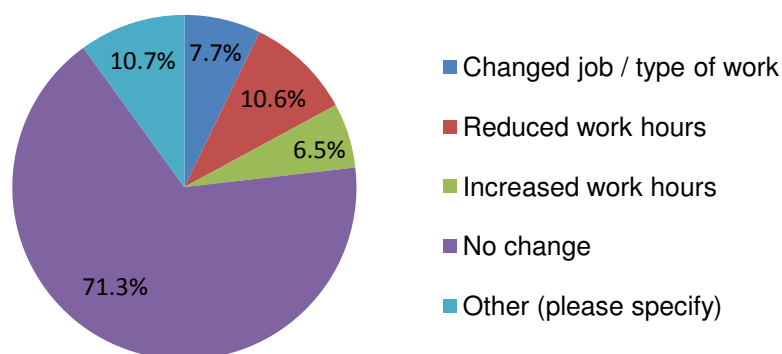


Figure 14: Impact on employment for a carer of a person with MS (perspective of person with MS)

#### 3.5.2 Views of carer of person with MS

13% of people taking the survey (1,148) did not have MS. While 97% knew someone with MS, 31% of these were carers of people with MS. 82% of these carers were in employment. As shown in Figure 15, being a carer of someone with MS had not affected 49%, while 16% had to reduce work hours, 10% had increased work hours and 8% had changed jobs/type of work indicating that 34% had been affected.

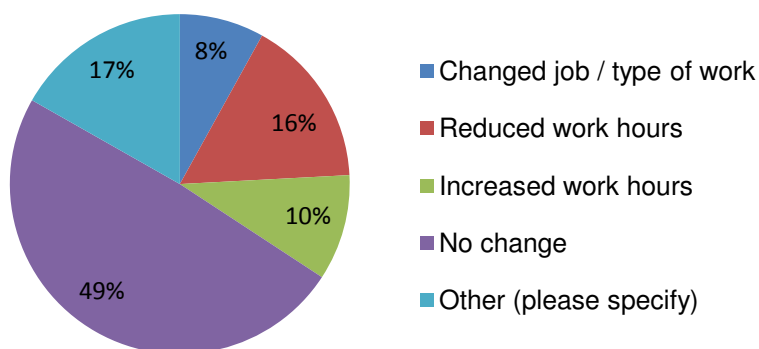
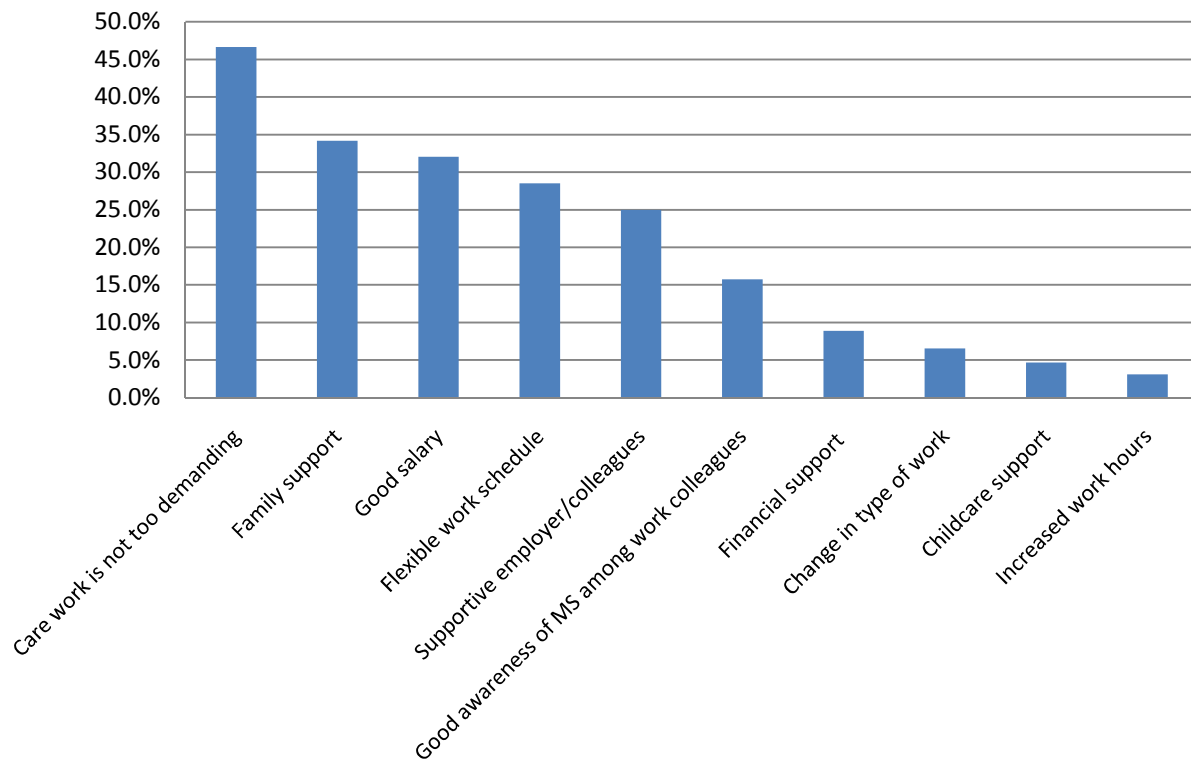


Figure 15: Impact on employment for a carer of a person with MS (perspective of carer)

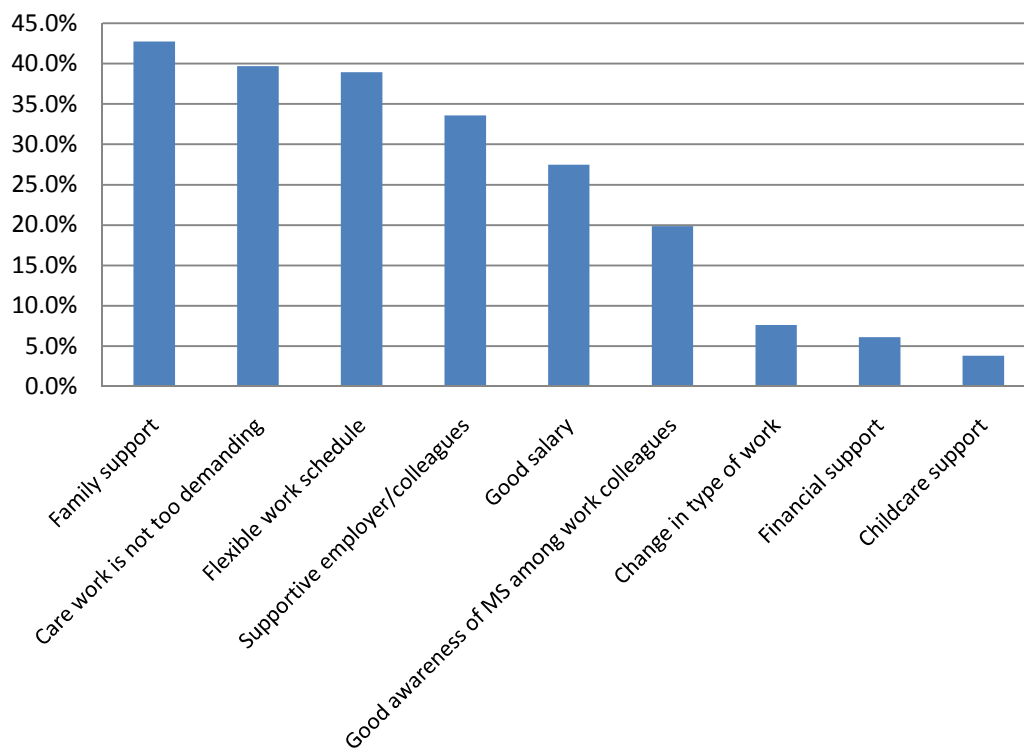
### 3.5.3 Factors that helped carers to remain in employment

When people with MS (N = 2,540) were asked which factors helped their carer to remain at work, 'care work not being too demanding' (47%), family support (34%), a good salary (32%), flexible work schedule (28.5%) and supportive employer/colleagues (25%) were listed as the most important factors, while childcare support (5%), increased work hours (3%) and change in type of work (6.5%) were listed as less important (Figure 16).



**Figure 16: Factors that people with MS considered important in helping their carer to remain at work**

A very similar response was obtained when carers of people with MS were asked the same question (N = 131). Figure 17 lists the factors that helped carers of people with MS to remain in employment. Family support (43%), 'care work not being too demanding' (40%), a flexible work schedule (32%) and supportive employer/colleagues (34%) were listed as the most important factors while childcare support (4%), financial support (6%) and change in type of work (6.5%) were listed as lower priority.

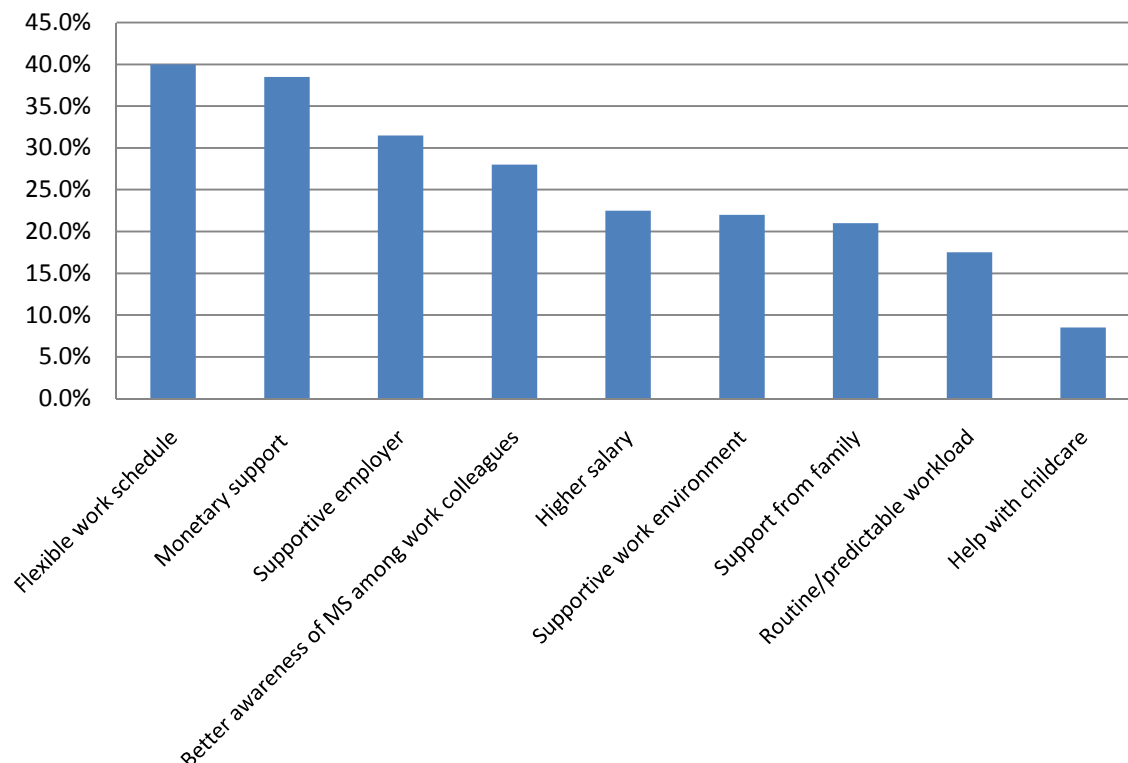


**Figure 17: Factors that enabled carers for persons with MS to remain at work**



### 3.5.4 Factors that would have helped carers to return to employment

People with MS whose carers were not in employment (N = 200), were asked to list the factors that would help their carer to return to work. As shown in Figure 18, a flexible work schedule (40%), monetary support (38.5%) and a supportive employer (31%) were listed as the most important factors while help with childcare (8.5%) and routine/predictable work load (17.5%) were listed as less important.



**Figure 18: Factors that people with MS consider important in helping their carer return to work**

## 4.0 Limitations

No sampling plan was used in the survey mainly due to the reason that while sampling is possible within individual countries, doing it on a global scale, particularly in countries that do not have MS societies and where reliable epidemiological data does not exist, is not feasible. The survey was linked to 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 ten languages. There are likely to be both similarities and differences between individual countries which are not discussed in this report.

## **5.0 Conclusions**

A striking result of the survey is that a majority of respondents were of working age with 76% being between 19-60 years. A majority of people were diagnosed for less than five years, giving a younger and less disabled sample with a shorter disease duration than is typically seen in similar studies. This may explain the finding of a higher percentage of people with MS still in employment (59%) compared to other studies. However it was interesting to note that despite being a comparatively younger sample, 67% of those who have remained in employment still found that having MS had at some stage impacted on their work.

Having stable MS was rated as the most important factor enabling people with MS to remain in work. This highlights the importance of disease management and the challenge of managing common symptoms such as fatigue from an early stage. This is supported by the fact that symptomatic treatments and disease modifying drugs were also rated as major factors. Studies have shown that the number of people remaining in employment has increased in the 2000s compared to the 1980s and this may in part be explained by improved treatments and better disease management.

Seated work, flexible work hours, and routine or predictable workload also rate highly demonstrating that flexibility in the workplace is key. Simple, inexpensive measures can make a big difference and are relatively straight forward solutions that can be put in place by employers. Surprisingly, technology related solutions were listed as low priority. Possible reasons are that such technologies are under-utilised due to a lack of knowledge or fears about cost.

Having a supportive employer and colleagues was also identified as one of the key factors enabling people with MS to remain in or return to work. This highlights the importance of educating employers and people in the workplace about MS. Family support was also listed as an important factor suggesting that family counselling, emotional and neuropsychiatric support can be of great benefit to people with MS and their families.

The fact that almost half the people leaving the workforce did so within three years of being diagnosed was a striking result. The reasons for this are not clear but it poses many questions. Did they leave voluntarily? Was it due to the lack of knowledge of legal protection available to employees, to not fully exploring options to manage symptoms while remaining at work, a lack of flexible work options, following advice to reduce stress or a reassessment of lifestyle and priorities? Although one would expect better disease management and treatment at early stages of the disease to improve these

figures, the high numbers leaving work so early suggests that drug treatments may not be as effective as hoped for or are not being used to maximum benefit at this stage.

Fatigue and mobility issues were cited as the major factors affecting a person's ability to work. This is in agreement with other studies of this kind. Surprisingly, cognitive impairments did not rate as highly as found in previous studies. This is one of the most challenging symptoms to manage on the job and its importance may be underestimated in the survey due to reluctance by people with MS to reliably acknowledge this problem.

In agreement with previous studies, the survey showed that although caregivers play a very important role, being a carer for a person with MS does not appear to have a huge impact on their employment. However, almost 30% of carers responded that being a carer had in some way affected their work. *The Global Economic Impact of MS*, a recent study commissioned by MSIF showed that the largest share of nonmedical costs of MS is for informal care. However, these estimates don't take into account work loss by informal carers, mainly family members. As this survey shows that almost a third of the caregiving population have found that their work is affected, it is important to account for this in future research into economic costs of MS.

Interestingly, the same factors, namely flexible working and family support, were important to both carers and people with MS, in helping them to remain at work. In addition, 'care work not being too demanding' was also listed as a major factor by carers, again highlighting the importance of disease management. It also underlines the importance of carers being supported at home financially and socially.

In summary, living with MS has profound implications on employment for many people from a very early stage. While there are no adequate measures yet to manage symptomatic factors such as fatigue, better information for people with MS on disability rights and availability of services, more research to provide better treatments and better disease management and relatively simple changes in the workplace, such as flexible working practices, should help people with MS to continue working for longer.

## **6.0 Recommendations**

Extending the possibilities for people with MS and their carers to stay in work is a challenge for governments, employers, medical professionals and MS Societies. The outcomes of this survey lead us to make the following recommendations:

- Provide information for people with MS and their carers to help them fully explore options to remain in employment, understand their rights and know what services and support (medical, financial and social) are available.
- Advise people with MS on how symptom and disease management can help whilst staying in work.
- Ensure early intervention, to get people with MS to seek help before a crisis point is reached, and to provide information on employment to those newly diagnosed. Employment should be considered as part of the overall management of MS.
- Educate employers and people in the workplace on issues related to MS and how to support people with MS at work. Employers need to be given information on useful workplace adjustments and the benefits of flexible working, routine workloads and rest breaks.
- Provide social, emotional and financial support for both people with MS and their carers.
- All governments to ratify the UN Convention on the Rights of Persons with Disabilities and ensure that national legislation is in place to provide support for people with MS and others with disabilities and ensure the absence of discrimination.

### **For further details please contact:**

Dr Dhia Chandraratna  
Multiple Sclerosis International Federation  
3<sup>rd</sup> Floor Skyline House  
200 Union Street  
London  
SE1 0LX  
Tel: +44(0)20 7620 1911  
dhia@msif.org