



worldMSday
25 MAY 2016

Global MS Employment Report 2016



Cover image

Abdelmaseeh, 41, lives in Egypt and works for the Ministry of Housing.

“We are examples of how people are living with MS. We are people on crutches, people in wheelchairs and we’re all living and working. The world doesn’t end because we have MS. We show people how they can continue to live with MS.”

Photo: MSIF/Sima Diab

We would like to thank all of the people affected by MS who took part in the Global Employment Survey.

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About MSIF

The MS International Federation (MSIF) is a unique global network of MS organisations. The federation is made up of 47 member organisations from around the world, and has links to many others. Together we lead the global fight against MS and work to improve the quality of life of people affected by MS in more than 90 countries.

MSIF works to strengthen organisations in countries where there is little support for people with MS. We campaign for increased awareness, provide information, and support international research into better treatments and ways to manage the disease.

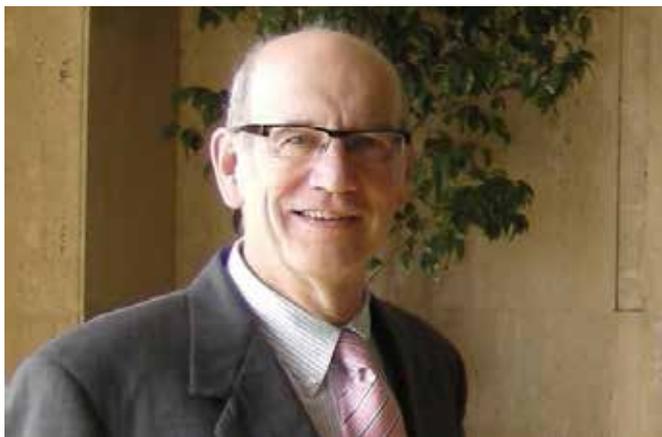
Our vision is a world without MS. Our mission is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding of the treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

For people with MS and their families, support and information are vital, as is the knowledge that scientists around the world are collaborating to develop better treatments for MS and to find a cure. MSIF is helping to make this happen around the world.

World MS Day

World MS Day was started by the MS International Federation and its members in 2009 as a way to bring the global MS community together to share stories, raise awareness and campaign with and for everyone affected by multiple sclerosis.

Foreword



People who live with chronic disease face unique issues navigating employment. No matter where we live, often our jobs define us - for better or worse. When a person with multiple sclerosis or other chronic conditions desires to work, that person and their employer face numerous issues - some legal, some moral, and some practical.

During the first decades of the MS movement, people with MS had little or no protection against employment discrimination because of disability. Moreover, in the early years of MS treatment, not only employers but also medical advisors assumed that all people with a diagnosis of MS should seek disability retirement from work.

The disability rights movement transformed the way that people with disabilities perceived themselves and the way that the public perceived them.

Every individual is different, this movement proclaimed. No one should assume that because of a diagnosis a person cannot perform essential job functions. Employers should remove obstacles to a qualified person performing their job and accommodate reasonably the job to the person.

The fruits of the disability rights movement were enshrined in law, for example in the Americans with Disabilities Act (1990). The ADA protects people with disabilities from discrimination and requires employers to make reasonable accommodations.

Despite such laws, the MS movement must remain vigilant to protect the rights of people with disabilities. The difficulties encountered in gathering approval of the Convention on the Rights of Persons with Disabilities only underlines the need for vigilance.

The MS International Federation works to advocate for employment rights of people with disabilities. It aims to educate people with MS and employers about making reasonable adjustments and the value of hiring people with MS and other disabilities.

This report offers evidence for advocating for oneself or a family member to ensure that people with MS are treated fairly and lawfully at work. When the public and employers understand what people with MS or other disabilities can offer in the workplace, both individual workers and employers will benefit.

Weyman T. Johnson Jr.
President and Chairman, MSIF

Introduction

A diagnosis of MS shouldn't mean someone has to give up working. Some people make a personal choice to leave employment, often due to the severity of their symptoms, or perhaps due to the perspective an MS diagnosis can bring to one's life plans. But the truth is that many people feel they have no choice but to leave a job, even though they are willing and able to stay.

The nature of how we see 'work' is changing, with traditional working hours changing in favour of flexible working. Technology makes remote working a reality and the freelance economy offers more flexible options than ever. At the same time society is beginning to recognise the work done by parents, caregivers, and volunteers. These unpaid roles remind us that, while employment provides an income (which is an important part of independence), both paid and voluntary roles can provide a sense of purpose, community and self-esteem. These all play a part in maintaining independence.

The good news is that the things people have told us would help them to stay in work are achievable. We're not looking for one solution, but a combination of small changes which would have a huge impact on the lives of people affected by MS.

Access to employment is listed as one of MSIF's 'Principles to promote the quality of life of people with MS'¹ and, as a federation, we will continue to push for this right, but we can't do it alone. We need good employment laws to protect people affected by disabilities and chronic illnesses and we need employers to enforce those laws and cultivate a culture where diversity and equality are celebrated.

We know that a lack of awareness is often the root of discrimination, so we need the population at large to be aware of MS. People with MS should have access to accurate information about their rights and the resources that are available to help them stay in work.

While some countries have taken strides forward in terms of employment for people affected by MS, others need serious change. This report serves to remind us of what we've achieved as a movement, but that the pace of change is slow.

We hope that this report will help people affected by MS and MS organisations to raise awareness of employment issues, and to advocate to governments and employers to speed up positive change in workplaces around the world.

¹ <http://www.msif.org/about-us/advocacy/principles-to-promote-quality-of-life/>

Overview of the sample

12,233 people took part in the 2015 survey, an increase of 40% from when we carried out the same survey in 2010. Respondents were based in 93 countries. 77% were female and 94% had MS, a figure which was consistent across the regions. The ratio of female to male respondents reflects the fact that there are twice as many women than men with MS.²

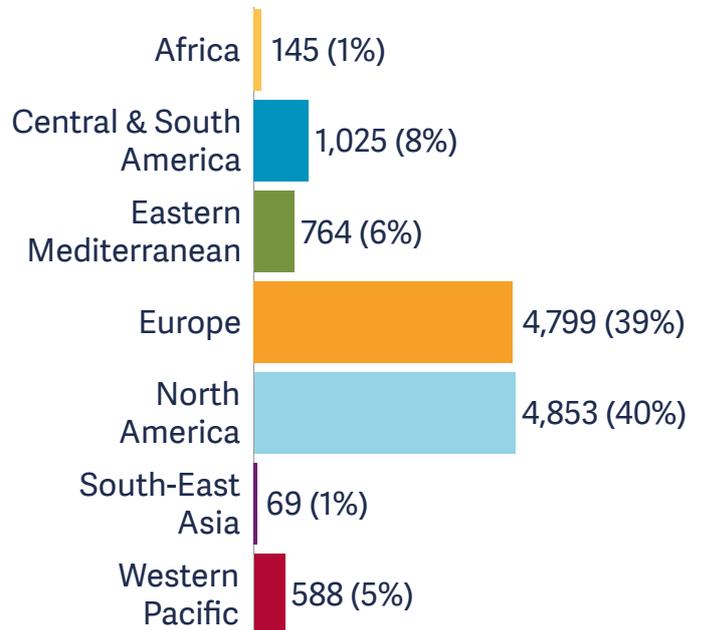
The majority (79%) of respondents were from either Europe or North America. A very small number were from Africa or South-East Asia. This regional distribution means that the results may not fully capture the global employment situation.

Most of the respondents were aged between 31 and 60. This reflects what we know about the age distribution of people with MS and the fact that MS tends to be diagnosed between 20 and 40 years of age, although onset may be earlier.³

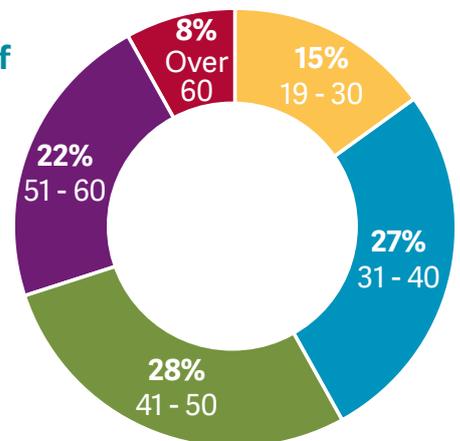
60% of respondents with MS had been diagnosed within the last ten years. This was true for both men and women. This was also broadly the case across all of the regions except for Central and South America and the Eastern Mediterranean, where respondents tended to have been diagnosed more recently.

Of the 718 respondents without MS, 44% had a partner or spouse with MS, and 37% had a family member with MS. This varied by gender as 50% of men had a partner or spouse with MS and only 20% had a family member with MS, whereas these figures were 26% and 47% for women, respectively.

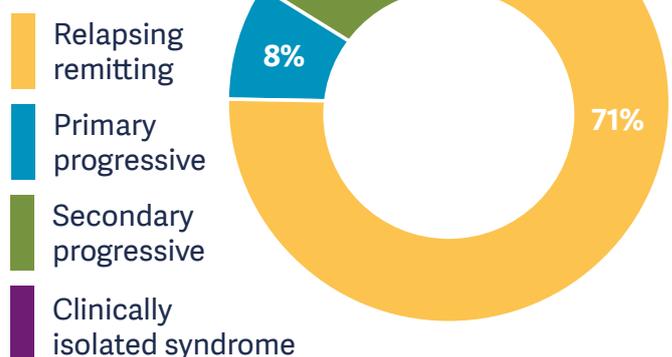
Number of responses received by region



Age distribution of respondents with MS



Percentage of respondents with each type of MS



^{2,3} MSIF (2013) Atlas of MS 2013



Sanket, 38, lives in India. He was diagnosed with MS at age 25.

He is a mechanical engineer and runs his own company manufacturing car parts, employing 200 staff.

All of Sanket's colleagues are aware of his MS, including his clients.

Photo: MSIF/Atul Loke

Key Findings

- **43% of people with MS who were not in employment had stopped working within three years of diagnosis. This figure rose to 70% after ten years.**
- **62% of people with MS who were not in employment said fatigue prevented them from staying in work – far less than the 85% reported in 2010.**
- **Fewer people had reduced their working hours or taken a short term absence compared to 2010 data.**
- **More people reported not needing to change their working pattern compared to 2010 data.**
- **Effective changes and adaptations could keep more people with MS in work.**
Many of the changes required to enable people with MS to stay in employment, such as adaptations in the workplace or access to treatments, are achievable through advocacy.

Recommendations

Employers

- Understand the nature of MS so that if an employee discloses their diagnosis you can ensure the workplace is supportive. Remember that MS is different for everyone, so ask people what they need.
- Have the work environment assessed by professionals who understand the needs of a person with MS and can suggest adaptations to accommodate them.
- Be aware of the potential effects that being a caregiver for someone with MS can have and how this could affect the caregiver's ability to work.

MS organisations

- Provide information for people affected by MS to help them explore options to stay in work, understand their rights and know what services and support are available.
- Encourage access to appropriate treatments. This includes disease modifying treatments to help manage MS and occupational therapy to support people in the workplace.
- Provide information and training to people with MS to help them to educate their employers and colleagues on issues related to MS and how to support people with MS at work.
- Share the results of this survey so that people know their voices are being heard and that the topic of employment is of critical importance to the global MS community.

Policy-makers

- Ensure that, where they exist, laws to prevent disability discrimination are well publicised and enforced. Where such laws do not exist, introduce legislation and protect the right to work regardless of disability, in line with the Convention on the Rights of Persons with Disabilities.⁴
- Require employers to make reasonable adjustments to the workplace when necessary.

⁴ <http://www.un.org/disabilities/convention/conventionfull.shtml>

Recommendations

People with MS and caregivers

- Take an active role in managing your MS and consider telling your employer about it, so that they can make reasonable adjustments to your work environment and workload as soon as possible.
- Ensure that you and your employer are aware of what support you are legally entitled to.
- Discuss your condition with family and friends so that people around you know what to expect and can be supportive.

Further research

- Qualitative research should be carried out into the relationship between employment and MS, to develop understanding of how the disease affects employment. Such research should investigate whether employment has a positive impact on health.
- There needs to be more research into whether intervening soon after diagnosis is a critical factor which could help people to stay in employment, as this survey indicates may be the case.
- Further research should be done on the relationship between MS and employment in specific regions. This would better capture the country-specific nature of employment and MS.
- Given the discrepancies between how caregivers and people with MS answered some questions, more research should be done into the employment situation of caregivers.

People with MS in Employment

This section looks at the nature of the employment people with MS have. It explores the amount they work, the type of work they do, and if any changes have been made to their working patterns. It also asks which factors have been important in helping them to stay in employment.

Proportion of people with MS in employment

61% of respondents (7,046) with MS were in employment, which is similar to the 59% reported in 2010. This was consistent by gender but not by age, where employment rates were higher for people aged 19 to 40.

The decline in the proportion of people over 40 in employment suggests people with MS are leaving the workforce at a young age. The relationship was similar across all regions although the percentage of people with MS in employment was slightly lower in the Eastern Mediterranean (54% in employment) and North America (54% in employment).

Nature of employment

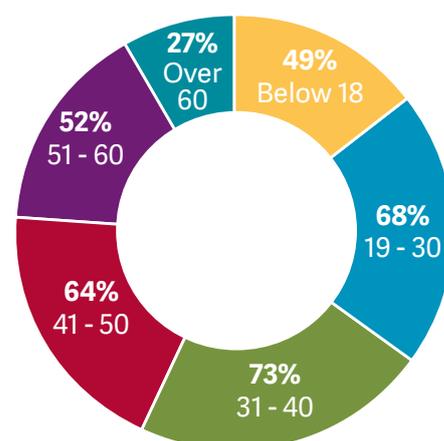
68% of people who worked were in full-time employment and 26% were in part-time employment, which is very similar to the 2010 data (68% full-time, 27% part-time).

The proportion of people in full-time work differed by gender, with 76% of men in full-time employment and 16% part-time, compared to 66% of women in full-time employment and 28% working part-time.

There was also variation by age. The proportion of people in full-time work decreased with age, falling from 73% of people aged 19 to 30 working full-time to 49% of those over 60 working full-time.

There was some regional variation, the proportion of people with MS in full-time employment was higher in South-East Asia (84%) and lower in Western Pacific (58%).

Percentage of people with MS in employment by age



Regional variation

The Disability Benefits Consortium survey (UK) showed that of the people with MS who were working 42% were in full-time work, 42% were in part-time work (16-35 hours per week), and 16% were in part-time work (0-16 hours per week), which suggests that there is some variation beneath the headline figure.



Regional variation

The Societal Cost of MS in Ireland report (MS Ireland, 2015) showed that 70% of people with MS who were working felt that MS had limited their career potential. The current survey did not address the effect of MS on career potential, but the finding from MS Ireland suggests the need for more research in this area.

People with MS in Employment

Changes in working pattern

39% of respondents with MS who were in employment said they had not changed their working hours, 18% had had a short term absence, and 16% had reduced their working hours. This was similar for men and women, although a greater proportion of men had changed job due to MS (13% compared to 8%). Compared to 2010, fewer people have reduced their working hours (27% in 2010) or taken a short term absence (25% in 2010). More people reported that no change had been needed.

People under 40 were generally more likely to take a short term absence while those over 40 were more likely to reduce the number of hours worked. The proportion of people who reported no change to their working hours reduced with age from 44% of people aged 19 to 30 to 37% of people over 60.

There were regional variations, with long term absences much more common in Africa (13%), Central and South America (13%) and South-East Asia (15%) than the worldwide proportion (7%). This could be

indicative of factors preventing people with MS from staying in employment, e.g. a lack of accessible buildings, or stigma around MS, and should be investigated.

The survey did not explore the full range of changes to working patterns, such as working outside the traditional workplace. Such changes may enable people with MS to stay in employment, so future studies should look into this in more depth.



Regional variation

A 2014 survey conducted in the UK, found that 77% of people with MS in employment agreed that their health limited the number of hours available to work. The difference found in this global survey could be due to many countries not having the workplace flexibility found in the UK, so people may be working despite pressing health needs.



Laura works at FEM-CET, an employment centre in Spain for people with MS and other physical disabilities.

The office is equipped with the necessary adjustments required by its staff. Staff are trained to provide telemarketing and administration services, to support them to rejoin mainstream employment.

Photo: MSIF/Natacha Elmir

People with MS in Employment

Factors enabling people with MS to stay in work

People with MS who were in employment were asked which factors have helped them to stay in employment.

Stable MS and treatments (disease modifying and symptomatic) were the most important factors for enabling people with MS to stay in work.

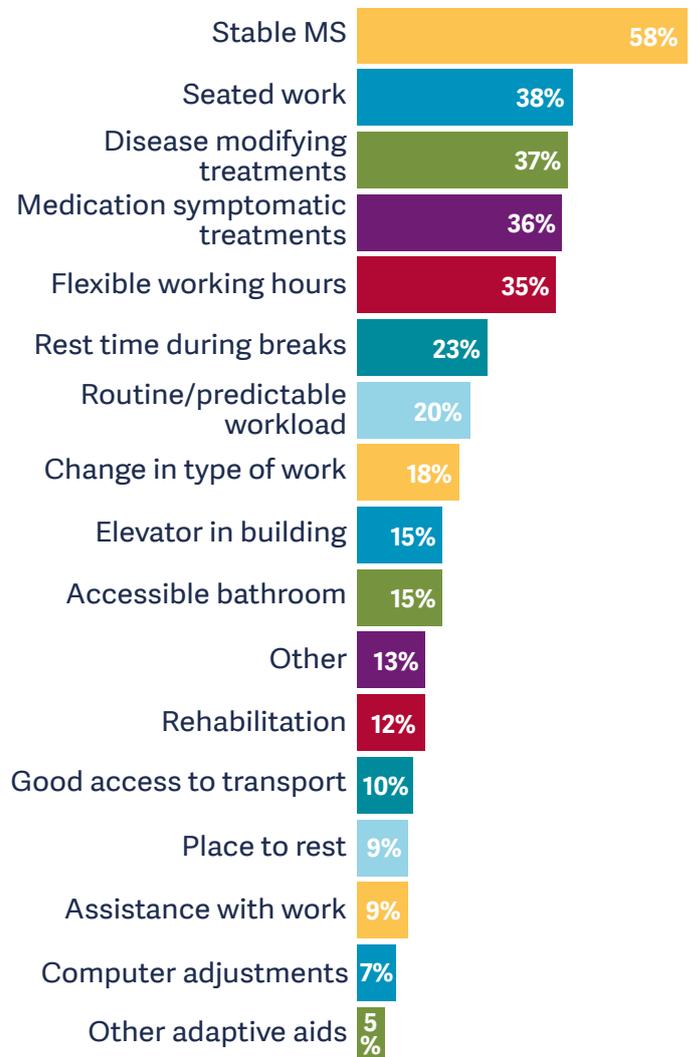
Among work-related factors, seated work (38%) and flexible working hours (35%) were the two most common.

People with MS said that support from family (50%) and employer/colleagues (42%) were the most important support-related factors that have helped them to stay in employment.

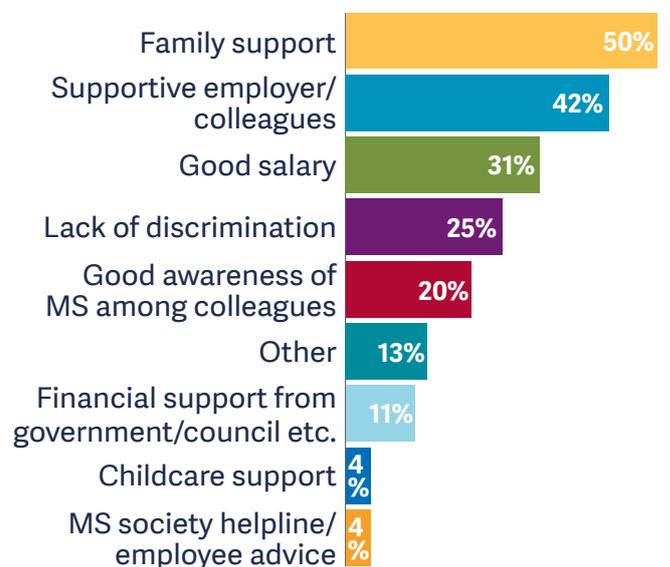
There was little difference between genders, age groups and regions in importance assigned to these factors. However, childcare support was more likely to be selected by women than men (89% of people who selected this factor were women). Childcare support was also more important for people aged 31 to 40 than other age groups and for people in Europe more than people in other regions. This raises an important issue: the impact of having a chronic condition does not act in isolation and it will intersect with other factors affecting employment, such as gendered patterns of caring or the age at which people are likely to have children.

This highlights the need for advocacy for people with MS to challenge gendered expectations about providing care, since the disease is more common in women and, in many societies, women take on the role of providing childcare as well as having paid work.

Work-related factors that have helped people with MS stay in employment



Support-related factors that have helped people with MS stay in employment



People with MS not in Employment

Of the 11,515 people with MS who took part in the survey, 4,469 (39%) were not in employment at that time. This section examines why they are not working, how long ago they stopped, what led to them leaving employment and what would help them return.

People not working due to MS

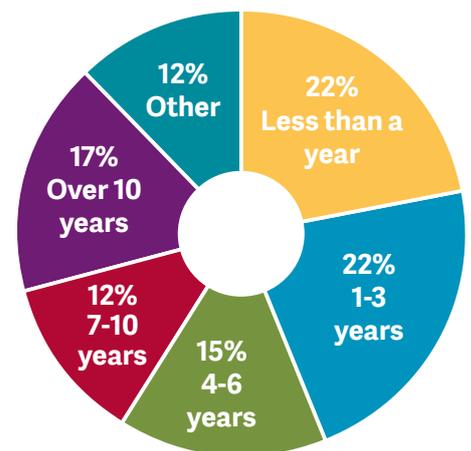
82% of people not working (3,649) said that this was due to their MS, which is a similar to the finding in 2010. There was little difference between genders but there was a variation by age. Only 55% of respondents aged 19 to 30 who were not in employment put this down to MS whereas for people aged 41 to 60 this rose to 90%. This may be because MS has a greater impact on older people and is affected by age and other conditions. The proportion of people not working who said that this was due to their MS was much lower in Africa (63%), Central and Southern America (71%), and the Eastern Mediterranean (54%).

Time between diagnosis and leaving employment

43% of people who were not working had stopped work within three years of diagnosis. The combined figure for people leaving within ten years of diagnosis is over 70%. In 2010, the figure was similar, 47% stopped work within three years of diagnosis. However, in South-East Asia, Western Pacific, North America and Africa people with MS worked for a longer time before leaving employment.

This is a very large proportion of people to be leaving work so soon after diagnosis. It could be that people with MS are leaving the workforce earlier than necessary due to a lack of workplace support or lack of information about how they could stay in work. This suggests that there could be a window in which an early intervention can be made to stop people leaving the workforce sooner than necessary. This needs further exploration given the positive impact it could have.

Number of years after diagnosis people with MS not in employment stopped working



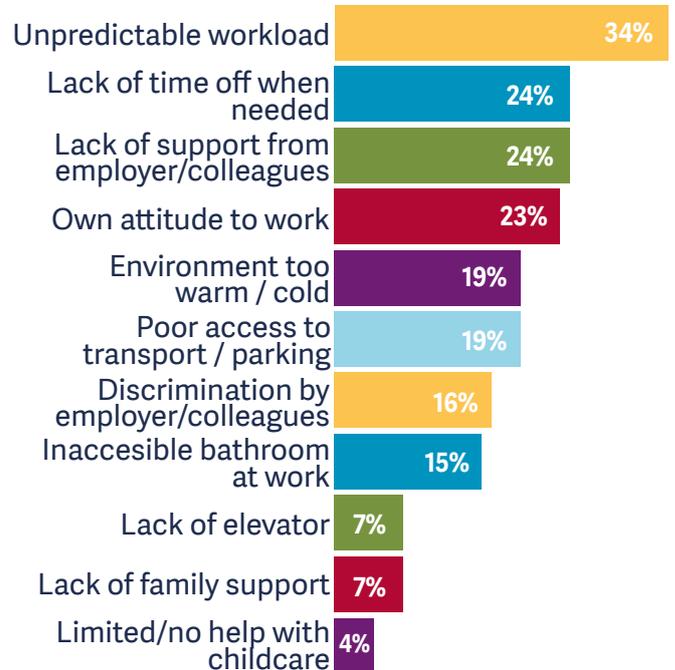
People with MS not in Employment

Factors preventing people from staying in employment

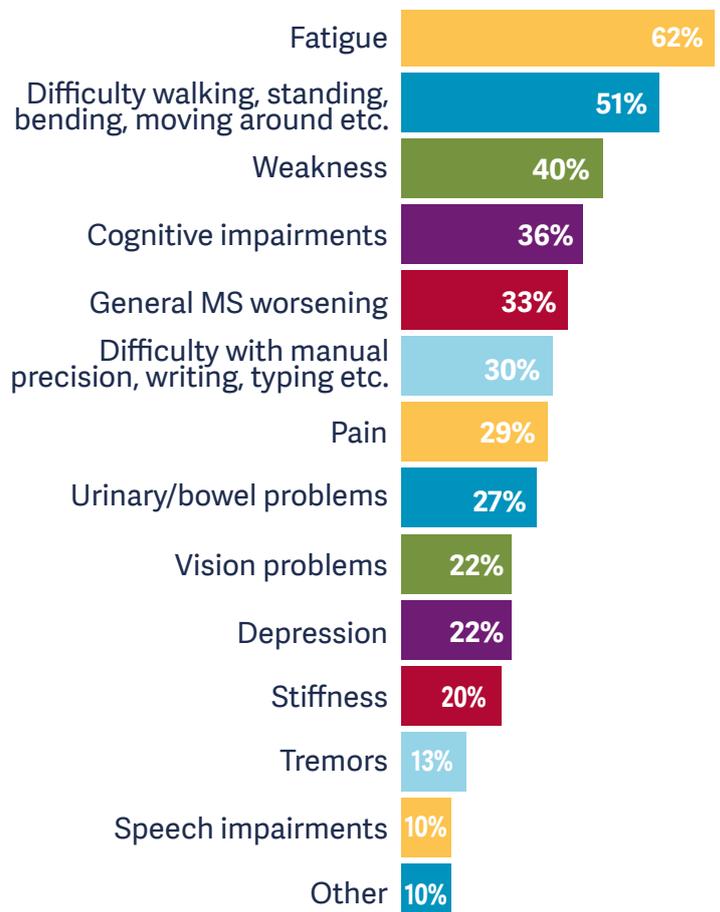
Respondents with MS who weren't in employment were asked which work-related and symptom-related factors had prevented them from staying in employment. Fatigue was the most common factor, with 62% of people saying that it prevented them from working. This is a large proportion of people, but it is far less than in 2010 when the figure was 85%. The other top factors were difficulty moving (51%), unpredictable workload (34%) and weakness (40%). The same things ranked highly in 2010. The factors which prevented people staying in employment can be changed through advocacy, treatment or making changes in the workplace.

The high ranking of fatigue highlights the importance of managing this symptom. However, the large improvement from 2010 suggests that activities to either reduce the problems caused by fatigue, or fatigue itself, may be working more effectively. Women and people aged 31 to 40 were more likely to highlight a lack of childcare support as a problem. Not having support from their own family was mentioned more often by people over 60. These findings are in line with the points raised earlier in this report about the intersection of age, gender and MS, and further emphasise the need to address how these factors may exacerbate problems caused by MS.

External factors that prevented people with MS from staying in employment



Symptom-related factors that prevented people with MS from staying in employment

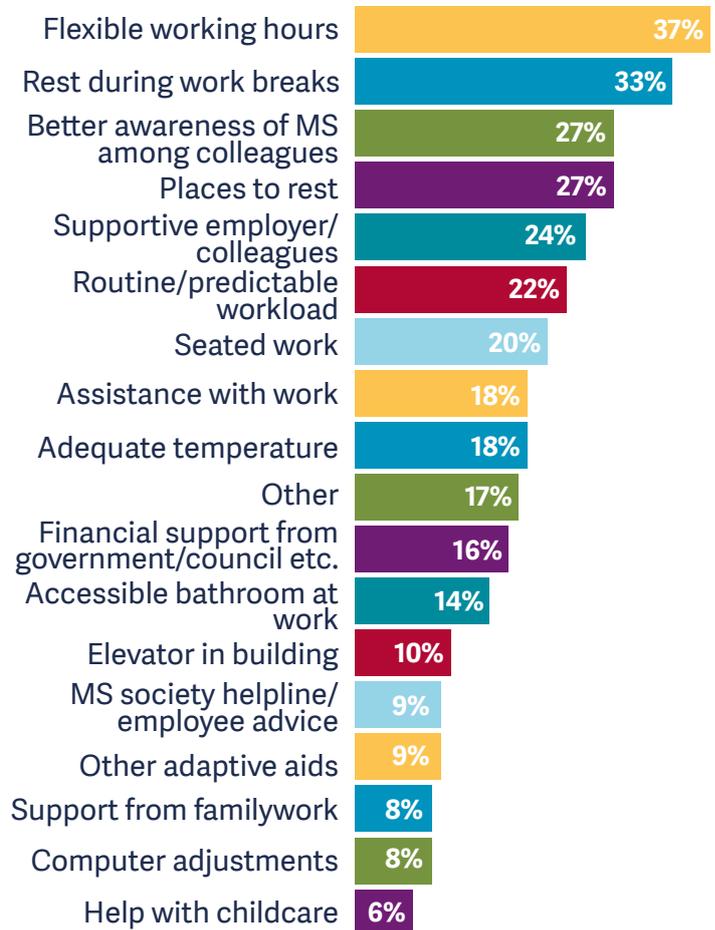


People with MS not in Employment

Factors that would enable people to stay in employment

Respondents with MS who were not in employment were asked what would have helped them to stay in work. The most popular factors were flexible working hours (37%) and resting time during work breaks (33%). Having help with childcare was more likely to be selected by women and people aged 31 to 40. There was little variation between regions but respondents from Europe were less likely to pick temperature control, computer adjustments and family support, while North American respondents were less likely to highlight the need for an elevator.

Factors that would enable people with MS to stay in work



Maarten was diagnosed with progressive MS when he was 52.

Three years later, his employer of 39 years relocated and the commute was too long.

He now works part-time at Nieuw Unicum, a centre for people with progressive MS in the Netherlands, where he is a resident. Here he can choose the hours he works and manage efficiently with limited energy.

Photo: MSIF/Chris de Bode



Comparison of people with MS in and out of employment

This section examines the differences in disease duration between people with MS who are in employment and those who are not. It should be noted that these results may be confounded by other factors which differ between the two groups, such as age.

Duration of MS in people in and out of employment

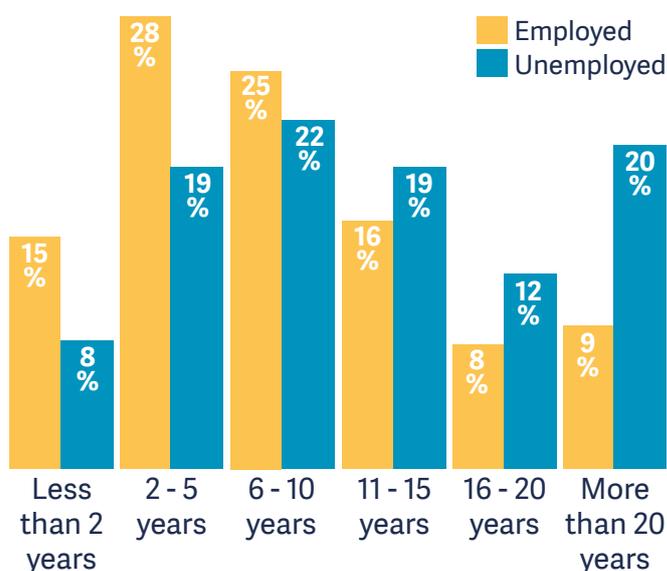
Given the findings shown earlier in this report, people who are not in employment would be expected to have had MS for longer. The results of the survey confirmed this, as people in employment had typically had MS for a shorter period of time, with 68% of people in employment having had MS for less than ten years compared to 49% of people not in employment.

Types of MS in people in and out of employment

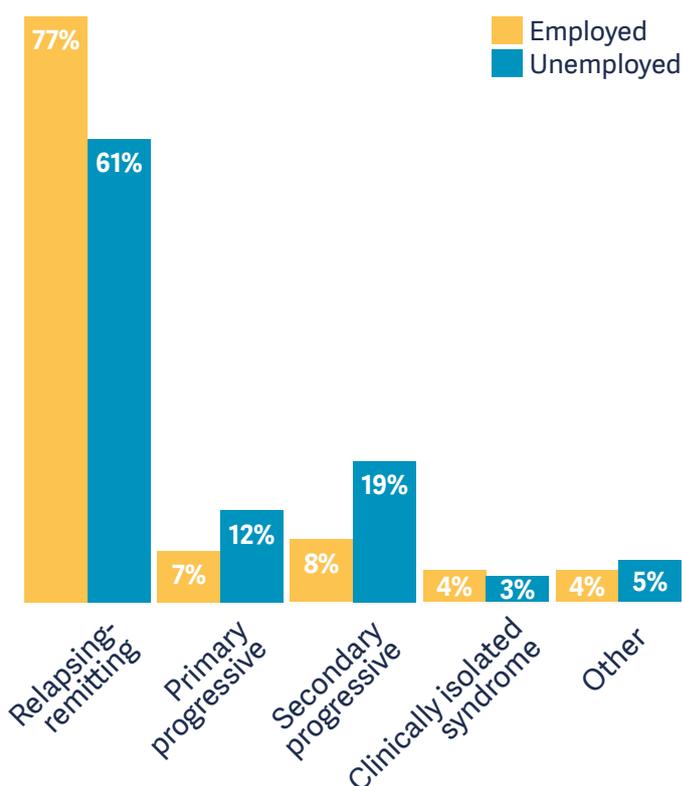
The survey shows that people with MS who are in employment are much more likely to have relapsing-remitting MS than those not in employment (77% compared to 61%).

In contrast, people not in employment are more likely to have either primary progressive MS (12% compared to 7%) or secondary progressive MS (19% compared to 8%). This is an important relationship to note since it may mean that people with progressive forms of MS will need more support to stay in employment and the level of assistance can be tailored accordingly.

Duration of MS by employment status



Type of MS by employment status



Caregivers of People with MS

We asked people with MS about their caregivers' employment status as well as asking caregivers directly. This section explores both sets of answers. Only 166 caregivers completed the survey so some results are only available from the perspective of respondents with MS, of whom 5,870 gave answers about a caregiver.

Caring for a person with MS can have an impact on the caregivers' employment. This impact should not be underestimated. Caregivers are defined here as people who provide unpaid care to children, spouses, parents, other relatives, friends or neighbours who have MS.

Is the caregiver in employment?

People with MS reported that 75% of their caregivers were in work. This figure varied according to gender so that this was more often true if the person with MS was a woman (78% compared to 68%). The opposite was true when caregivers were asked directly, which reported that 73% of female caregivers were in employment compared to 89% of male caregivers. People with MS who were older were less likely to have a caregiver who worked, with just 44% of caregivers of people over 60 being in employment. This may be due to additional complications caused by the person with MS being older or because the caregiver themselves is more likely to be older and not in work. In Central and South America, caregivers were more likely to be in work (81%) and the opposite was true for the Eastern Mediterranean (67%).

Effect of being a caregiver on employment status

Of the 1,439 caregivers not in work, 20% were described as not working due to the respondent's MS. In contrast, when caregivers were asked directly this figure was much higher at 54%. This may indicate discrepancies between the perception of the person with MS and the caregiver, which emphasises the importance of surveying caregivers directly.

Both people with MS and caregivers cited men as more likely to have left employment due to caring for someone with MS. Where the person with MS was under 18 or over 60 the caregiver was less likely to have stopped work to look after them, but more likely to have changed their work.

In all regions apart from Europe and North America, caregivers were more likely to have stopped working to care for a person with MS.

People with MS said that, of the caregivers who continue to work, 71% had not changed their work, 8% had increased their working hours, 9% had reduced their working hours, and 4% had changed their job. These results are very similar those found in 2010.

Caregivers in Africa and South-East Asia were more likely to have increased their working hours. It may be that caregivers increased their working hours to increase income in order to deal with costs associated with MS.

When asked directly, 54% of caregivers had not changed their working pattern, 20% had reduced their working hours and 4% had increased their working hours. Female caregivers were more likely to change their working pattern than men (60% compared to 50%).

Caregivers of People with MS

Factors that helped caregivers stay in employment

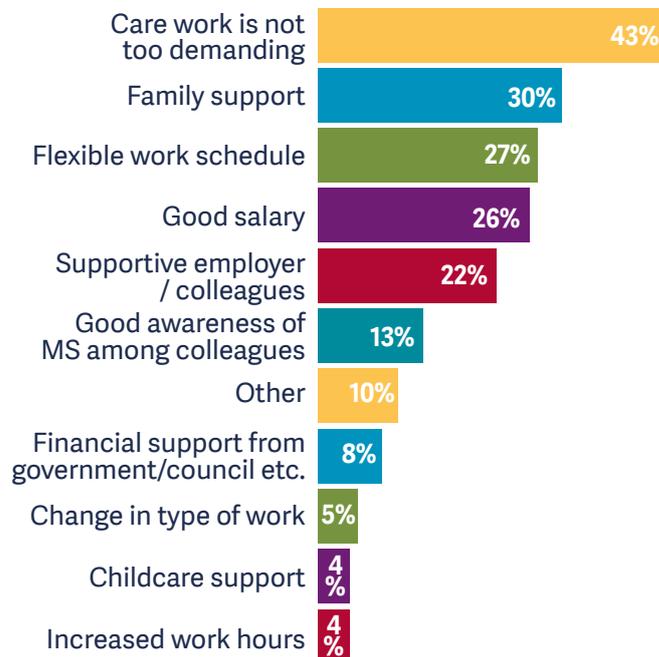
People with MS who had an employed caregiver were asked what helps their caregiver to stay in work. The most important factor was that the care work was not too demanding (43%), followed by having family support (30%) and a flexible work schedule (27%).

Factors that would help caregivers return to employment

People with MS whose caregiver was not in employment were asked what would help their caregiver start working again.

Very few people selected any of the available factors provided in this question. This suggests that the factors listed were generally not considered the most effective way to assist caregivers in returning to work. However, it may also be that it is harder to determine which factors would hypothetically help when the caregiver is currently not in work, compared to determining what actually did help them stay in work.

Factors that helped carers stay in employment



Concluding Remarks

Many of the findings in this report are very similar to those from 2010. In some areas there have been important changes, particularly the finding that, compared to 2010, more people have said that they haven't needed to change their employment situation. This suggests that measures taken to improve the position of people with MS in the workplace are effective. However, the results of advocacy and awareness-raising are more likely to be observed in the longer term. A global survey such as this may have masked important changes happening within individual countries.

A large proportion of people with MS who do not work had stopped working within three years of diagnosis, which is concerning. It may be the case that people with MS are leaving the workforce earlier than necessary due to a lack of support or insufficient information about staying in work. This suggests that there could be a window when an early intervention can be made to stop people leaving the workforce sooner than necessary. This merits further exploration given the positive impact it could have.

Many of the factors listed as important for keeping people in work can be changed, for both people with MS and caregivers. This means that action can be taken to support people affected by MS in the workplace. The importance of making changes in the workplace highlights the recommendation for people – where possible – to tell their employer about their MS at the earliest opportunity so that support can be arranged. This is a very personal decision and should be carefully considered and discussed, whilst bearing in mind that research has shown that there's a tendency to start making adjustments too late.⁵

⁵ RD Simmons, KL Tribe, EA McDonald (2010) 'Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management'

The effectiveness of individuals disclosing their MS has been assessed in an Australian study of 1,438 people which found that people who disclosed their MS diagnosis were more likely to be in employment after three years.⁶ It should be noted that this won't be applicable in all countries, particularly those with different employment laws, very competitive labour markets or stigma around MS.

The analysis of age and gender has provided insights which were not available in 2010. Women were more likely to highlight insufficient childcare as a factor that could affect their employment circumstances. Women were less likely to be in full-time employment than men. The impact of age on employment was also apparent, with the proportion of people in employment falling after 40, along with the proportion of people working full time, and the number of hours worked.

Some regional differences were also observed but it is important to consider the limitations of a global survey. Additional research should be conducted at regional and country level to determine what factors are preventing people with MS from working. In different regions the effect of MS – and its relationship to age and gender – will be very different, due to cultural, economic and legal differences.

In summary, although there have been some positive changes in employment for people with MS, further improvements are still needed. The work required to make these improvements may already be underway in many places, with advocacy campaigns to destigmatise MS and make it clear that people with MS can be valued members of any workforce.

⁶ AK Kirk-Brown, PA Van Dijk, RD Simmons, MP Bourne, BK Cooper (2013) 'Disclosure of diagnosis of multiple sclerosis in the workplace positively affects employment status and job tenure'

Methodology

Survey design and sampling strategy

The survey was based on the same questions as a previous survey conducted by MSIF in 2010, to enable comparison between the two periods. The survey was made available in ten languages: English, Arabic, Chinese, French, German, Hindi, Indonesian, Portuguese, Russian and Spanish, using the online tool Survey Monkey. The survey was intended to be answered by either people with MS or the caregivers of people with MS, and was distributed in late 2015.

Following feedback on the geographical distribution of the 2010 survey, the 2015 survey had a sampling strategy which aimed to recruit 1% of the known MS population in each country. The number of people expected to be recruited in each country and the number actually recruited is available on request.

Analytical strategy

Analyses were conducted for the entire survey sample and also divided into groups by age, gender and region to examine whether or not there was variation across these factors. Regions were assigned using the World Health Organization's categories⁷, except with a change to separate 'The Americas' into two continents: 'North America' and 'Central and South America'. A list of which region each country falls into is available on request. All analyses were conducted using the R statistical language and figures were produced using the ggplot package.

Limitations

The use of an online survey means that there is likely to be substantial bias in the sample, possibly towards people with higher socioeconomic status who may have better access to the internet. As such it is not possible to make comparisons with the general population since other data will have been collected using different methods and will have different sources of bias.

The survey questions use terms which may have multiple meanings, such as 'family support', without definition and this may mean that the interpretation of the results does not match the intentions of the respondents. Additionally, the survey does not ask whether people would like to stay in work and is based on the assumption that they do, which may not always be the case.

The sample contains a disproportionately large number of people from Europe and North America, which may make the results less representative of the situation in middle and lower income countries. For lobbying in individual countries it is likely to be necessary to collect country-specific data in order to develop persuasive arguments which relate to the particular situation in that country.

⁷ <http://www.who.int/about/regions/en/>



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