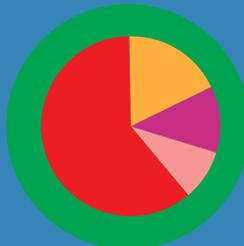


Multiple Sclerosis and Employment: Facts and Figures



MS & Employment

Employment is good for health



9,000
people in Ireland have MS

Average age of diagnosis is 32

9 out of 10 people with MS are of working age

€135.5m Productivity Loss

People with MS

General Population



34.2% Retired due to MS or unable to work at present

68% Feel MS has **limited** their career potential

Little difference in **overall job performance** between employees with a disability and those without



Recommendations

1. Stable disease activity – assisted by access to effective treatment
2. Supportive employers and colleagues
3. Seated work
4. Flexible work hours
5. Computer adjustments



MS Employment facts and figures

Global overview

Due to the early onset of the condition and long duration, MS impacts heavily on the lives of those with the condition. As a consequence of disease activity and symptoms of MS, disruption of work, social and family life are common.

The employment-related consequences of MS have been well documented across Europe. High levels of withdrawal from the workforce have commonly been reported (Kobelt et al., 2006b, Karampampa et al., 2012a, Taylor et al., 2007).

This restriction in professional activities, allied with symptoms such as fatigue and cognitive strain can precipitate feelings of isolation and often depression which exacerbates reductions in quality of life (QoL) of those with the condition (L. Ford, 2001). Estimates of lifetime prevalence of depression are higher for a person with MS – by some estimates up to twofold the experienced in the general population (Arnett and Randolph, 2006, Horwath et al., 1992). On the positive side however, numerous studies show that employment is good for health. Employment provides a higher standard of living, greater social integration and a sense of self-worth.

MS is associated with productivity losses for two main reasons. Firstly, since the average age of disease onset is between 20-40 years, MS impacts people at a key phase of their working life. Secondly, some 60% of people with MS will experience relapses that – in moderate to severe cases – can affect mobility, exacerbate fatigue, and may require hospital level care. The unpredictable and periodic nature of relapses is also a key struggle in efforts to build and sustain a usual working life.

MS impacts heavily on the lives of those with the condition. Disruption of work, social and family life are common.

Numerous studies show that employment is good for health. Employment provides a higher standard of living, greater social integration and a sense of self-worth.

The impact of this unfortunate situation is reflected in several studies. The proportion of the participants in the Kobelt (2006) European study (N ≈13,286) who worked was low; with a between country range from a low of 25 up to a high of 40%. A more recent study is strongly suggestive of positive improvements in employment rates with the Multiple Sclerosis International Federation (MSIF) reporting 59% in 2010 and 61% in 2016. However these encouraging rates remain below the general population employment rates of 70.1% in the EU (Eurostat, 2016).

Permanently withdrawing from the workforce is a notable feature. Significantly, 35% of UK participants in McCrone et al. (2008) under 65 were in early retirement, as was 50% in the Norwegian study, 45% in the Austrian and Dutch arm of the Kobelt (2006) study and more than half of the people with MS (56%) in the recent Finnish study (Ruutiainen et al., 2015)

Expectedly, there is a relationship between disease severity and employment across Europe. In the Kobelt (2006) European study, 70-80% of people with mild MS (EDSS 0.0-1.0; minimal disability) were employed; however this percentage drops off precipitously with increasing disability. At moderate stage (EDSS 3.0; moderate disability but remains independent), close to 50% of people with MS are not in work (Giovannoni, 2013). At the very severe end (EDSS 8.0-9.0) only 10% of people with MS are in employment.

This study states that specific symptoms such as fatigue and cognitive performance have been associated with increased odds of becoming unemployed. The severity of depression has also been correlated to unemployment (Honarmand, 2011).

While it is clear that MS has a tremendous impact on the lives of those with the condition, the same is also true for their family members. During relapses and as the disease course progresses, a family member, in many cases a spouse, is required to adapt their lives to cope with the caregiving responsibilities associated with MS. Reduced working weeks and indeed having to permanently withdraw from the workforce are also commonplace for those who care for people with MS (Kobelt et al., 2006b, Karampampa et al., 2012a). Furthermore, the caregiving experience can be both physically and psychologically demanding and consequently may result in withdrawal from employment also.

With this in mind, the impact of MS on the individual and society becomes apparent.

Recently MS Ireland in collaboration with neurology clinicians, health economists, and hundreds of people with MS, undertook a key study to assess the true economic cost of MS to the Irish society overall.



Ireland

According to the last available census, 3% of the total workforce (or 52,299 people) have a chronic illness. An estimated 9,000 people in Ireland have MS.

Based on a representative sample of 595 people with MS, the results of our study represent the most comprehensive review of employment activity for people with MS in Ireland.

Employment Status (description)	%
Employed Full-time (over 30 hours per week)	31.7
Employed Part-time (less than 30 hours per week)	11.1
Student	4.2
Household duties	9.2
Retired (due to age)	4.9
Retired (due to MS)	27.3
Current unable to work but intent to return	6.9

- Almost 43% of our sample of people with MS living in Ireland reported working in paid employment and three-quarters of these were working full-time.
- This rate of employment is lower than the 60% average rate seen across Europe for people with MS.
- While Ireland does have a marginally lower rate of general workforce participation (68.8%) than the EU (70.1%), due in part to current economic conditions, the lower Irish rate of employment for people with MS (43% vs. 60%) is suggestive of a problem that is not purely economic or disease related. This difficulty with employment for people with MS in Ireland – whether attitudinal or systemic or both – may not be fully understood or appreciated at a policy level in Ireland.



An estimated 9,000 people in Ireland have Multiple Sclerosis.

The largest, most comprehensive review of employment activity for people with MS in Ireland

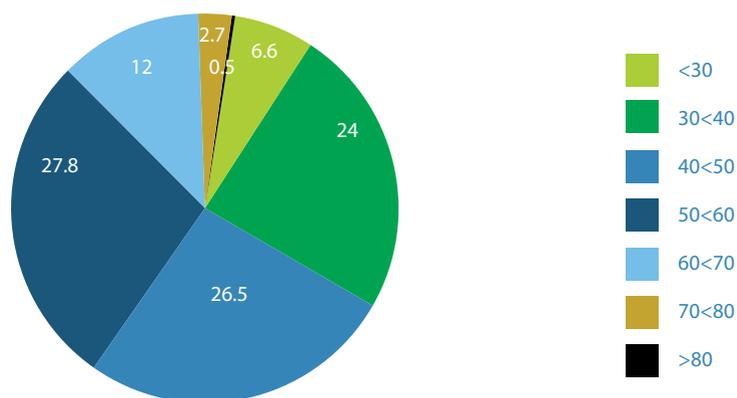
- However, despite lower rates, there is evidence that those in employment in Ireland are more likely to have full-time work (>30 hours per week).
- However, the lower proportion of people in Ireland with MS who are employed on a part-time bases may be suggestive of a difficulty achieving more flexible working hours arrangements for people with MS in Ireland, relative to the EU.
- Importantly also is the picture over time in Ireland. Information from MS Ireland indicates a substantially positive trend improvement in employment participation in Ireland over time – with particularly large strides forward in recent times.

9 out of 10 People with MS in Ireland are of working age

Sample Characteristics	%
Average age	47
Proportion under the age 65	91.9
Proportion over age 65	8.1

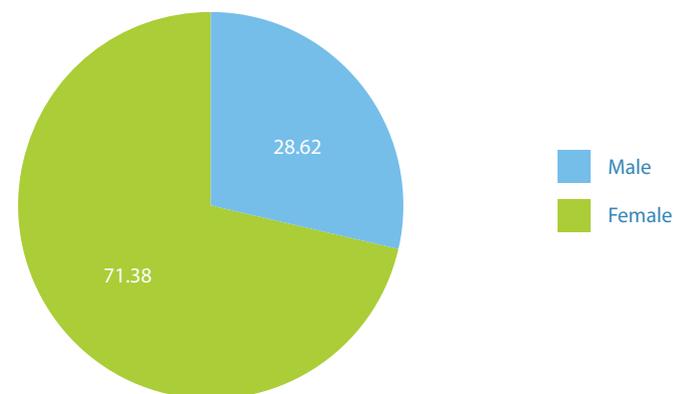
The average age and age distribution of MS is important from an employment perspective. Some 92% of people with MS are aged less than 65 years -- and thereby we can say that 9/10 are of working age. The sense in which productivity can be impacted on a societal level therefore also becomes clear. The cross-European experience shows that 92% of people with MS are under the age of 60 (MSIF Atlas of MS, 2013).

Age distribution



MS is thought to be at least twice as prevalent among women as men. The data from our study confirms this and is somewhat suggestive of the disease affecting proportionally more men in Ireland than in Europe. In most EU studies, the ratio of 77/23 is commonly reported (MSIF). However without a systematic epidemiological study in Ireland, no firm conclusion can be drawn.

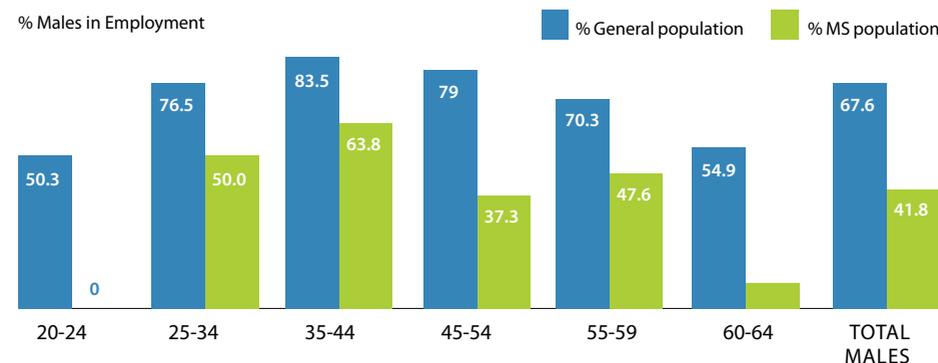
71% of people with MS in Ireland are female



MS is associated with lower rates of employment and greater premature retirement

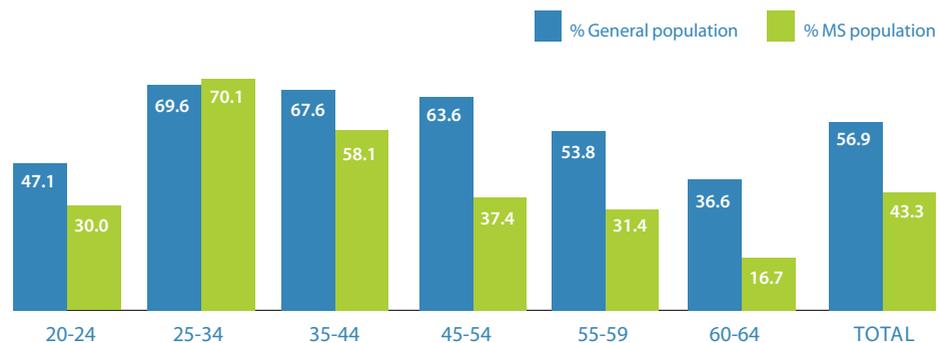
The principal factor driving the divergence in employment rates between those with MS in Ireland and the general population, is premature retirement associated with their MS.

Male population in Employment – General population & MS population



Female population in Employment – General population & MS population

% Females in Employment



In our study, 34% of men and 25% women reported having to permanently withdraw from the workforce. For those who have their working lives cut short, the experience is likely to have a negative impact on income and income development. This is true for both men and women with the condition in Ireland.

If we take the case of men in the 35-44 and 45-54 age groups in our sample, we see employment rates fall substantially over this 20 year time period (63.8% vs 37.3%). This decline is particularly notable when we consider general population earnings growth across this career period. In the general population, when comparing earnings between these two age cohorts, those aged 45-54 earn 12.4% more on average than those in the 35-44 category (€47,404 vs €42,173) (CSO, 2011).

Similarly for women in our sample, those aged between 45-54 are 47% less likely to be employed compared to those in the 25-34 cohort, while average income increases by nearly 18% across these age categories in the general population (€29,768 vs €25,251). This double-edged effect of rapidly decreasing employment rates at a time when average incomes would otherwise be increasing, leaves many of those with MS at a distinct disadvantage to their peers.

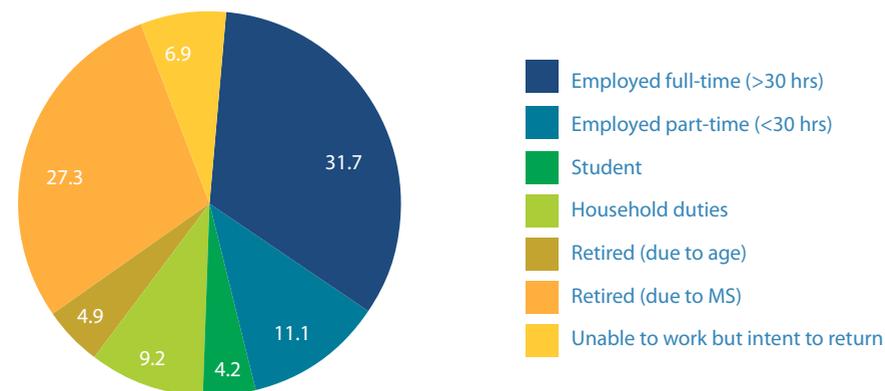
While finding and remaining in employment can be difficult for those with MS, it is also the case that the presence of symptoms related to MS can inhibit people with the condition while at work and consequently impact on productivity. There is some evidence that presenteeism, (i.e., reduced productivity while working) —may be a significant factor in the general population as well as for those with debilitating illnesses. As a case in point, a study examining the impact that arthritis has on work productivity estimated that presenteeism accounts for 41% of total productivity losses, while absenteeism constitutes 10% (Li et al., 2006). In total, for those in paid employment (n=254), the average percent of work performance affected by MS symptoms was 18.9%.

MS and Employment: Impacts, adjustments and permanent withdrawals

The sizable rate at which people feel their careers have been affected is consistent with the European data which shows that two thirds of people with MS say the disease has affected their job.

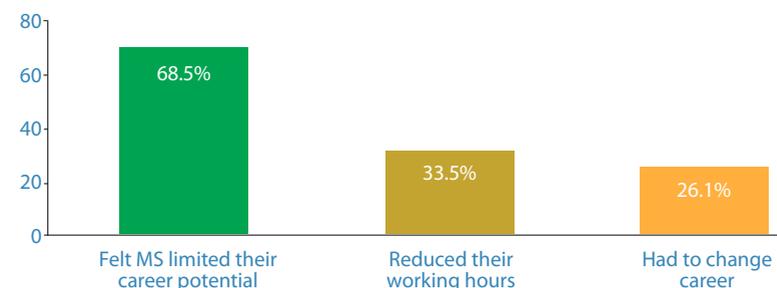
Just over 27% of our sample reported having to permanently withdraw from the workforce due to their condition.

Employment Status of people with MS in Ireland



- 33.5% of those working have officially reduced their working hours
- 26.1% felt it necessary to change career path
- 68.5% felt that MS had limited their career potential.

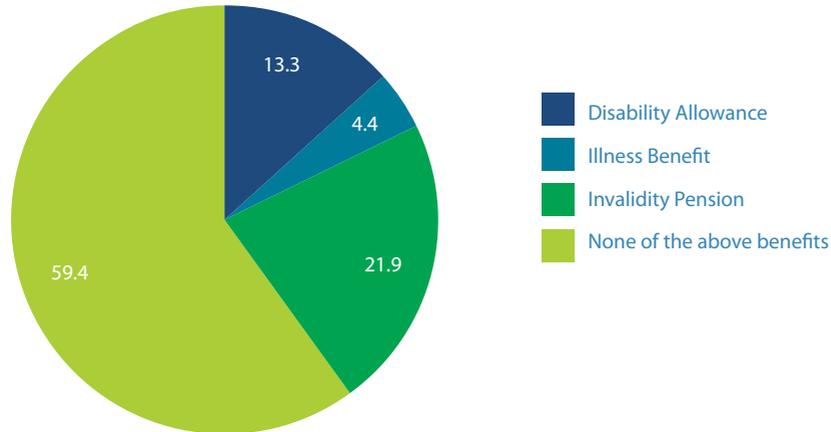
Effect of MS on Career



State Supports

In total almost 60% of our sample were not in receipt of a state benefit or welfare support for those withdrawn from the workforce.

State Support for People with MS in Ireland



Productivity losses amount to €135.5 million

In Ireland, the total number of equivalent work days lost due to MS is estimated at almost 930,000.

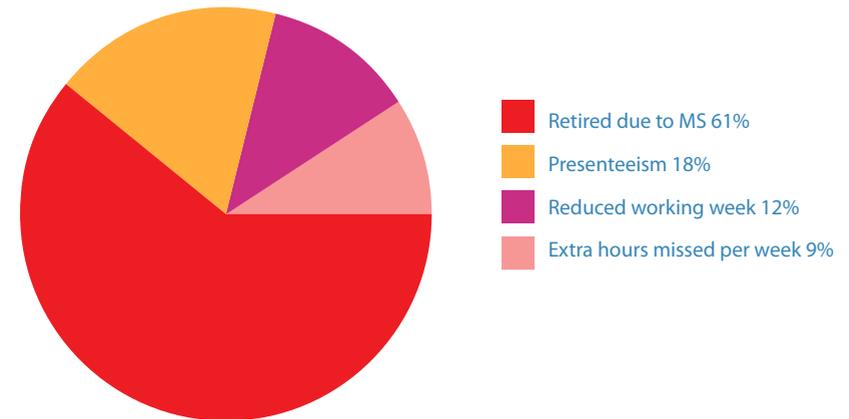
A considerable number of people reported having to permanently withdraw from the workforce due to their condition, in total 27% of our entire sample had done so.

The total days lost calculated from our sample was 61,372 and extrapolating to the national population of people with MS in Ireland, assuming a total prevalence of 9,000 people, provides an estimate of some 930,000 work-days lost due to MS annually.

We include an estimate for the costs associated with self-reported work performance (also known in employment as “presenteeism”). The estimated effect was between 18% and 21%. However, it is important to note that, while we include these estimated productive losses for completeness, researchers have found very little difference in overall job performance between employees with a disability and those without (Hernandez and McDonald (2010)).

In our study, the costs attributable to productivity losses are estimated at being €15,056 per person. Extrapolating to the national population with MS in Ireland, assuming a total prevalence of 9,000 people, provides an estimate of total annual costs attributable to productivity losses of €135.5million.

Productivity losses: €135.5 million annually



Total number of work days lost due to MS

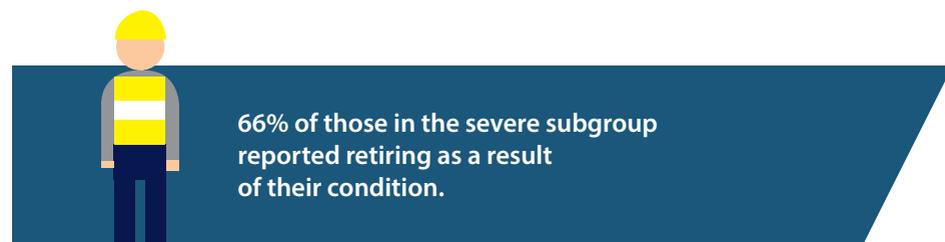
Employment variables	Days lost per year (Study sample, n=594)	Days lost per year (Extrapolated, n=9,000)
Officially reduced working week	6,351	96,220
Extra days missed in the last week, due to appointments, etc.	4,650	70,447
Retired early due to MS	38,868	588,909
Presenteeism	11,504	174,305
Total number of work days lost due to MS	61,372	929,881

Employment decreases with increasing disease severity

A significant relationship existed between disability severity and employment status; those with mild MS are more than twice as likely as those with moderate disability to be in paid employment, while a similar relationship exists when comparing those with moderate and severe disability, with employment rates of 26% and 15%, respectively.

Permanent withdrawal from the workforce due to MS is also predicted by disability severity; approaching 66% of those in the severe subgroup reported retiring as a result of their condition, this figure falls significantly when examining the moderate (39.8%) and mild subgroups (15.6%).

Significant differences were also apparent when it came to hours of informal care received in the previous week, those with severe MS requiring 2.7 times as many hours care than those with mild disability. While those with moderate MS reporting 56% more hours of informal care than those with mild MS and 40% less than those with severe MS.



Employment by disability severity

	Mild (n=342)	Moderate (n=211)	Severe (n=41)
Employment variables	Obs %		
In paid employment	56.4	26.1	15.0
Full time (over 30 hours)	43.3	16.6	15
Officially reduced working week (hrs per week)	16.0	13.7	2.4
Extra hours missed in the last week	9.6	8.5	7.3
Retired due to MS	14.9	39.8	65.8
Presenteeism (% of work performance affected)	25.4	26.1	14.6

Employment decreases with disease progression

A significant relationship existed between type of MS and employment status; 51% of those with RRMS were in paid employment, while for those with PPMS and SPMS fewer were working at the time of the survey; 27.2% and 21.8% respectively.

Permanent withdrawal from the workforce due to MS is also predicted by disease type; almost 55% of those with SPMS reported retiring as a result of their condition, 36.4% of those with PPMS to a low of 18.5% for those with RRMS.



Employment by disease course (RRMS, SPMS & PPMS)

	RRMS (n=374)	SPMS (n=97)	PPMS (n=66)
Employment variables	Obs %		
In paid employment	51.1	21.8	27.2
Full time (over 30 hours)	37.7	13.4	22.7
Officially reduced working week (hrs per week)	16.8	11.3	7.6
Extra hours missed in the last week	12.0	7.2	3.0
Retired early due to MS	18.5	54.6	36.4
Presenteeism (% of work performance affected)	25.4	16.4	16.7

Discussion

Since the average age of onset is between 20-40 years, and where 9 out of 10 people with MS are of working age, MS impacts on people during the prime of their working lives.

While more people with MS are in employment today than in the 1980s, due to better treatments and disease management, problems remain and further substantial improvements seem possible to bring Ireland's employment rates more in line with the cross-European experience.

Highlighting the work-life challenges associated with having MS is important. While legislation and changes in attitudes mean that workplaces are becoming more accommodating to staff with chronic disease – the statistics demonstrate that more could be done to enhance the work-life prospects of those living with MS in Ireland.

Improved employment opportunities and support for more flexible work practices will help in this regard. The Multiple Sclerosis International Federation's (MSIF) find five key factors emerge as being most helpful in helping people with MS remain in the workplace (Chandraratna, 2010):

1. Stable disease activity – assisted by access to effective treatment
2. Supportive employers and colleagues
3. Seated work
4. Flexible work hours
5. Computer adjustments

Recommendations

1. Access to interventions that reduce relapses and disability progression, support working and living independently
2. Improving employment opportunities



My Working Life with MS

Niamh McCarron



What (if any) adjustments have had to be made in your working environment?

Luckily, I haven't had to make many changes to my working environment. During the summer months (or days, let's face it - Ireland doesn't get summer months), I use a little desk-top fan to keep cool. I don't like a lot of heat, it causes my symptoms to flare up. I make sure my chair is comfortable, as I sometimes get pains in my legs. When that happens I'll have a little stroll around the office to shake things out a bit.

How has MS affected your work life?

MS Fatigue can be brutal, and when I am feeling rough I have to slow down a bit. Thankfully, I have mostly been able to rest during weekends and evenings, so it hasn't had too much of an impact on my working days. I have had 3 big flare ups since 2010, two of which landed me in hospital. During these episodes, work has had to take a back seat. My colleagues were great at helping me out with the jobs that were urgent, and rescheduling less important tasks for me.

What type of employment do you have?

I started working with PAN Research in 2007, so I've been here a long time. I work full-time, in an office based role. I spent 4 years working from home in Donegal, but I've recently returned to Dublin so I am now based in our Rathfarnham office.

Were you working when you were first diagnosed with MS? What type of work were you doing? What else?

I was diagnosed in 2010, so I had been working here for a few years by then.

Did you tell your employer about your diagnosis? Why (not)? How did they react?

We are a small company, so when I was going through tests for MS I kept my employer in the loop. This was partly because it was obvious something was wrong with me - I lost power in my right hand and had to get my boss to write stuff down for me - and partly because I am a chatty article, and I had told everyone I knew anyway.



What does the ability to work mean to you?

Everything. I don't think I'd cope with not working at all. Being in contact with my colleagues and clients, and having a demanding role keeps my brain ticking over. The social aspect - I enjoy getting out of the

house and seeing people every day, catching up with my colleagues' news in the office. Financially, it would have a huge impact on our household if I stopped working, which is another factor to consider.

Financially, it would have a huge impact on our household if I stopped working.

My Working Life with MS

Emma Hughes



Yes I was working full time in an extremely busy pharmacy. I was a dispensing technician - filling prescriptions and consulting with customers. I loved it but I was on my feet all day, every day. I was very fatigued which I found difficult to manage as I didn't feel I was succeeding in a work/life balance.

Did you tell your employer about your diagnosis? Why (not)? How did they react?

Yes I told them as I was absent for a month in hospital and recovery following a relapse and diagnosis. They were very supportive as they were also a HCP. Given our working profession I knew they would understand and realise the condition is manageable for me.

My current employer is also aware as I came into the company on an internship for PwMS and have since been kept on as an associate. I have found they treat me as any other colleague and judge me on my ability rather than focus on any disability. Luckily I am in

What type of employment do you have?

I work in an office, mostly sitting at a desk. It is full time employment and I can work flexi time hours.

Were you working when you were first diagnosed with MS? What type of work were you doing? What else?

good health and I have not been prevented from working due to living with MS.

What (if any) adjustments have had to be made in your working environment?

Due to large numbers of employees on site, parking is not always available to all employees. It was offered to me as I was recognised as an employee living with chronic illness. With flexi time I can chose to come in early and leave early. I find I am most productive in the mornings. This allows me to spend the evening at home resting as needed.

How has MS affected your work life?

I have chosen to change the direction of my career. I felt I needed a change of pace in my working life to prevent me from being completely fatigued in the evenings.

What does the ability to work mean to you?

The ability to work is extremely important to me. I want independent financial security and to continue to be educated through work. Working improves my quality of life and helps me to have a healthy daily routine. I want to keep working for as long as I can.

Anything else you feel is relevant

Work is a social and educational outlet for many. Through helping employers understand seeing people's abilities rather than disabilities, the work force can continue to support and employ valuable skilled workers who just happen to be PwMS. The adjustments in the workplace may be minimal – merely understanding and openness. There is more to us than just MS.



The ability to work is extremely important to me. I want independent financial security and to continue to be educated through work.

Working improves my quality of life and helps me to have a healthy daily routine. I want to keep working for as long as I can.

MS Ireland Call and Commitment

MS Ireland commits to monitoring and promoting social inclusion and workforce participation among the population of people with MS in Ireland. We call on all stakeholders to aim for greater parity with our European neighbours over the next three years.

Summary & Conclusions

Productivity losses as a consequence of MS are estimated at €15,056 per person with MS. This individual level costing is consistent with recent estimates from across the EU.

MS is associated with productivity losses for a variety of reasons. Since the average age of onset is between 20-40 years, MS impacts people at the prime of their working life. Furthermore, for those who experience relapses, or are unable to walk or who experience extreme fatigue, it can be difficult to sustain a normal working life. This is apparent in our study where 26% of those in employment, felt it necessary to change jobs due to their condition, while close to 70% felt that the disease had limited their career potential.

Consequently, for those with MS, finding and remaining in employment can be difficult. This is illustrated by the employment rates evident in our study, where 41.7% of men and 43.2% of women report being in paid employment. These figures represent a 24% and a 38% decrease on the national averages for women (56.9%) and men (67.6%), respectively (CSO.2014). Our employment figures are broadly consistent with a previous Irish study (Fogarty et al., 2014) who found an employment rate of 40.1% in a smaller clinic-based sample in Leinster. As one would expect employment status varied by disability severity in our study (mild: 56.4%, moderate: 26%, severe: 15%) and disease type (RRMS: 51.0%, SPMS: 21.9%, PPMS: 27.2%).



MS Ireland commits to monitoring and promoting social inclusion and workforce participation in Ireland.

Improvements in the management and treatment of MS mean that people with MS, and the right employer supports, can remain in the workplace and retain financial independence for themselves and their families. However, a multi-pronged approach—with partnership across health, enterprise and employers—is required to promote full inclusion of people with MS in work and society.

This report has helped to highlight the current state of employment participation in Ireland. It has demonstrated that while employment trends for people with MS in Ireland are positive, we are still lagging a great deal behind our European neighbours in terms of rates of participation. The figures suggest that part of the issue may be more difficulty in finding flexible working arrangements that serve to dissuade and discourage people with from retaining their financial independence, and fulfilling their career objectives.

Preventing this disease from progressing will keep a large percentage of people with MS working and independent



MS Ireland Policy Recommendations

1. Early intervention guidelines

Development of specialised early intervention guidelines to support those absent from work to return to work as soon as possible when and where appropriate. These guidelines should specifically account for the needs and experiences of those living with long-term chronic illnesses and how the symptoms of illnesses such as MS impact on work. These guidelines should be developed by the National Disability Authority in consultation with people affected by the condition and organisations and professionals who support them.

2. Workplace assessment services

Access to appropriate and timely workplace assessment services from specialists who have a detailed understanding of particular illnesses and conditions. These specialists may be occupational therapists or organisational psychologists who have received training in particular disability or illness areas, or professionals from relevant support organisations who have received training in undertaking assessments. Assessments should be conducted in consultation with the multi-disciplinary team of healthcare professionals who are working with the employee. The Employer Disability Information Service should have a role in supporting employers to identify and access specialist assessment services.

3. In-work supports

Access on-going in-work supports for both employers and employees. Existing 'job coach' services should be expanded to support job retention for those returning to a position after the diagnosis of a chronic illness or acquisition of a disability. Existing financial supports for employers, such as the Retention Grant and the Workplace Equipment Adaptation Grant, should be expanded in scope so as to cover additional in-work supports such as fares to work if the employee can't use public transport or drive, or employment of a support worker or job coach to provide support in the workplace, as per the Access to Work model in the UK.

4. Retraining services

Appropriate post-employment planning, including access to retraining services and vocational rehabilitation services where necessary. Existing services that provide advice and guidance on employment and education should be expanded and upskilled so as to be able to provide guidance that specifically accounts for the needs and experiences of those living with long-term chronic illnesses such as MS.

5. Avoid a 'welfare trap'

Extension of entitlement to medical cards and other associated benefits on return to work, to avoid a 'welfare trap.'

Defining Terms: Types of MS

Relapsing-Remitting MS (RRMS) This is the most common form of multiple sclerosis. About 85% of people with MS are initially diagnosed with RRMS. People with RRMS have temporary periods called relapses, flare-ups or exacerbations, when new symptoms appear².

Secondary-Progressive MS (SPMS) In SPMS, symptoms worsen more steadily over time, with or without the occurrence of relapses and remissions. Most people who are diagnosed with RRMS will transition to SPMS at some point³.

Primary-Progressive MS (PPMS) This type of MS is not very common, occurring in about 10% of people with MS. PPMS is characterized by slowly worsening symptoms from the beginning, with no relapses or remissions².

About MS Ireland



Multiple Sclerosis Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and other interested in or concerned about MS to ensure that we meet our goals. MS Ireland is chiefly a services driven organisation, focused on providing timely, person-centered services that create independence and choice for person with MS and their family.

www.ms-society.ie

For more detailed review see The Societal Cost of MS in Ireland (McGuigan, O'Rourke et al., 2015). Published and available from MS Ireland.

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