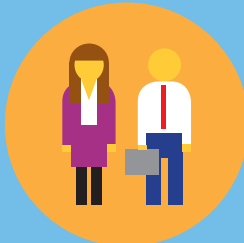
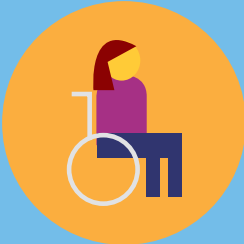


# Quality of Life

of people living with MS in Ireland



**9,000** people with MS in Ireland

Quality of life is rated **32% less** than for the general population

**80%** of people with MS experience pain and discomfort

**78%** struggle to do their usual activities

**92%** experience fatigue due to MS

**60%** experience anxiety and depression

**FACTORS AFFECTING QUALITY OF LIFE IN MULTIPLE SCLEROSIS:**

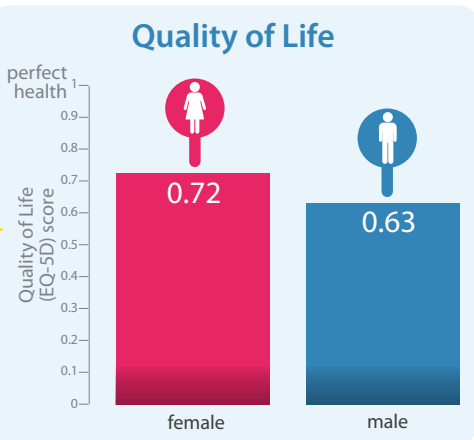


- Employment status
- Reduction in relapses

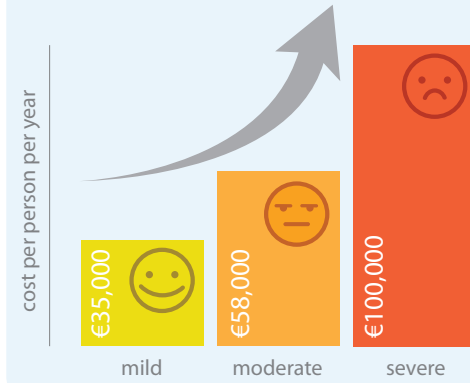


- Confirmed relapses
- Disease severity
- Age

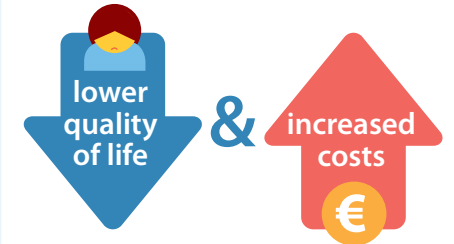
Men with MS have a lower Quality of Life than women



Disability progression is associated with increased costs:



Progression in MS is associated with

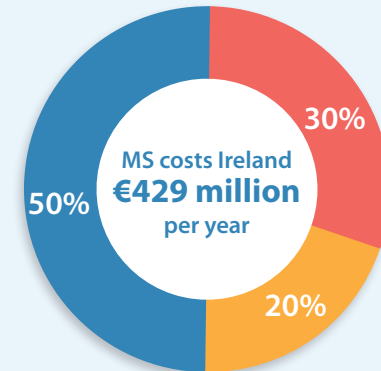


investments that slow progression have a significant societal benefit

**MS is associated with HIGH costs.**

Most of these are *OUTSIDE* the healthcare system.

**Indirect costs**  
(e.g. time off work, carers)



**Direct cost**  
(e.g. hospitals, doctors, medication)



**Intangible costs**  
(e.g. Quality of Life)

**People with MS**

**43%** Working in Ireland

**60%** Working in EU

are flexible hours an issue?

**General Population**

**70%** general population employment rate in EU

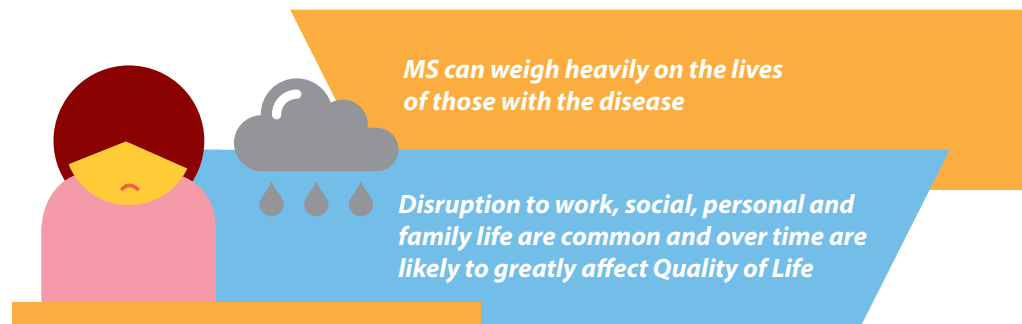
## Introduction

Multiple sclerosis (MS) is a complex inflammatory disease of the central nervous system (CNS). The onset of the disease is typically between 20 to 40 years of age<sup>1</sup>, and up to 9,000 people live with this chronic condition in Ireland.<sup>2</sup> As well as functional impairment and disabilities, symptoms of MS include visual disturbances, abnormal speech, swallowing disorders, fatigue, bladder and bowel problems, as well as other sexual, mood, and sensory impairment.<sup>3</sup> At the onset, approximately 80-85% of all people with MS are diagnosed with the relapsing–remitting (RRMS) form of the disease, which may over time progress to the secondary progressive phase (SPMS). Some 10-15% of people with MS will present with primary progressive MS (PPMS) from the outset.

The burden of MS in economic terms was examined in recent work by McGuigan et al (under review). At a societal level, the total cost is €429 million per annum; of this €134 million relates to direct healthcare costs, €214 million relates to indirect costs and the remaining €81 million per annum of intangible costs is an economic estimate of the Quality of Life burden of MS at the national level.

Therefore some 70% of the total costs associated with MS are ‘hidden’; they are not routinely counted at the national level. This work also shows how annual costs increase with disability and disease progression at the individual level – from €35,000 per annum for mild, to €58,000 for moderate, to €100,000 for severe MS – and provides an economic argument for managing (eg. by reducing relapses) and slowing the progression for the illness.

On the human level, due to the young age at onset and chronic course of the condition, MS can weigh heavily on the lives of those with the disease. Disruption to work, social, personal and family life are common and over time are likely to greatly affect Quality of Life. This analysis, for the first time in a large nationally representative sample, describes the Quality of Life impact for people living with MS in Ireland and identifies factors that determine and mediate Quality of Life for people living with MS.



## Data Gathering

### Online Survey

A survey was developed to capture the demographic, disease, healthcare use, informal care, employment and wellbeing of people with MS. Referencing international studies, standardised survey instruments were included (e.g., CSRI, MFIS-5, EQ-5D) or adapted (EDSS) for inclusion in an online survey platform.

People with MS living in Ireland were recruited via an MS Ireland mailing list and social media, as well as through print media.

595 people completed the survey in full and, of these, 541 completed the detailed Quality of Life questionnaire (EQ-5D-5L).

### The Quality of Life Scale

The EQ-5D-5L is a measure of Quality of Life. It measures five key areas of well-being – mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. For each area, the respondent indicates their degree of difficulty with that area with a five point scale from ‘having no problems’ to ‘having extreme problems’.

Responses to these questions can be compared to the scores from the general population, to determine the reduced level of Quality of Life of the sample.

**Table 1: The five domains and five levels of severity of the EQ-5D-5L instrument**

<b>5 Domains:</b>	<b>Mobility</b>	<b>Self-care</b>	<b>Usual activities</b>	<b>Pain/Discomfort</b>	<b>Anxiety/Depression</b>	
<b>5 Dimensions:</b>	Having <b>no</b> problems	Having <b>slight</b> problems	Having <b>moderate</b> problems	Having <b>severe</b> problems	Being unable to do/having <b>extreme</b> problems	

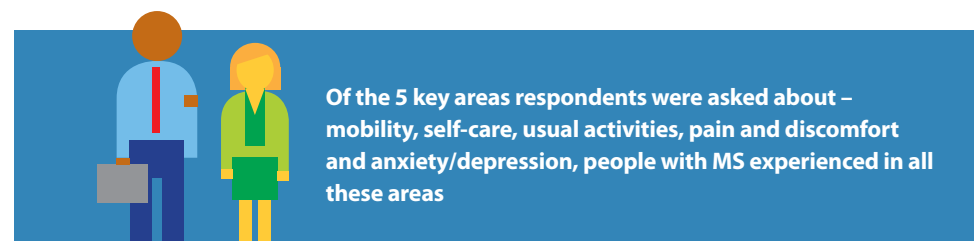
## What the Sample Looks Like

### Characteristics of the Sample

As with the MS population, our sample was mostly female (71%), with 65% married and 62% having children. 42% of the sample were in employment and 77% had a long term illness card. In the sample 64% had the relapsing-remitting form of MS, with 17% having the secondary progressive form and 10% having the primary progressive form of the disease, the remainder being unclear or having clinically isolated syndrome. The sample had a fairly normal distribution across ages with the average age being 47 years.

**Table 2. Characteristics of the sample of MS patients**

Patient Characteristic	n=541
Average Age	47 years
Female (%)	71%
Married	66%
Children	62%
Employed	42%
Province	
Connaught	12%
Leinster	58%
Munster	24%
Ulster	5%
State benefits	
Disability allowance	14%
Illness benefits	6%
Invalidity Pension	22%
Received no state benefits	58%
Long Term Illness Card	77%
MS type	
Relapsing-Remitting	64%
Secondary Progressive	17%
Primary Progressive	10%
Hours of informal care (past week) average	12 hours
Disease Duration	7 years
Duration of symptoms before diagnosis	4.4 years
Confirmed relapse (past year)	23%
Disease Severity	
Mild	58%
Moderate	35%
Severe	7%



Of the 5 key areas respondents were asked about – mobility, self-care, usual activities, pain and discomfort and anxiety/depression, people with MS experienced in all these areas

<b>Pain and Discomfort</b>	Almost 80% of people with MS surveyed experienced pain and discomfort and this was the highest of the variables measured
<b>Usual activities</b>	Over three quarters of those surveyed had some problems – ranging from mild to severe – with completing their usual daily activities
<b>Mobility</b>	The next biggest issue for people with MS is mobility. 72% had some issue with mobility
<b>Anxiety and Depression</b>	3 in 5 of the group surveyed have issues with anxiety and depression
<b>Self-care</b>	3 in 5 of respondents said they had no problems with self-care

The issues for people with MS vary from person to person as it is a very individual condition, however, large numbers are suffering from pain and discomfort (not a well known part of MS), and difficulties with usual activities and mobility are commonplace.



## Men have a Lower Quality of Life than Women

Figures 3a and 3b shows the differences in Quality of Life scores by sex across the full sample, and then within each of the three disease categories (mild, moderate, severe). It appears clear that, while the mean scores for men and women are the same at lesser stages of disability, the scores for men widen with progression, suggesting a lower Quality of Life experienced by men, as reported by the sample.

Figure 3a: EQ-5D scores by sex

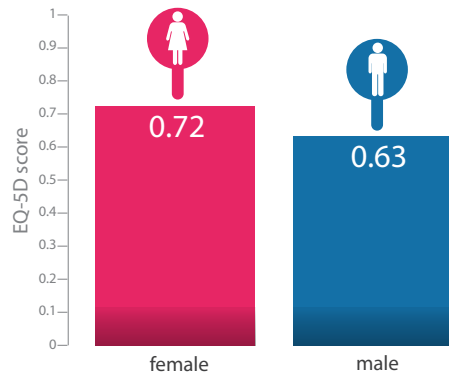
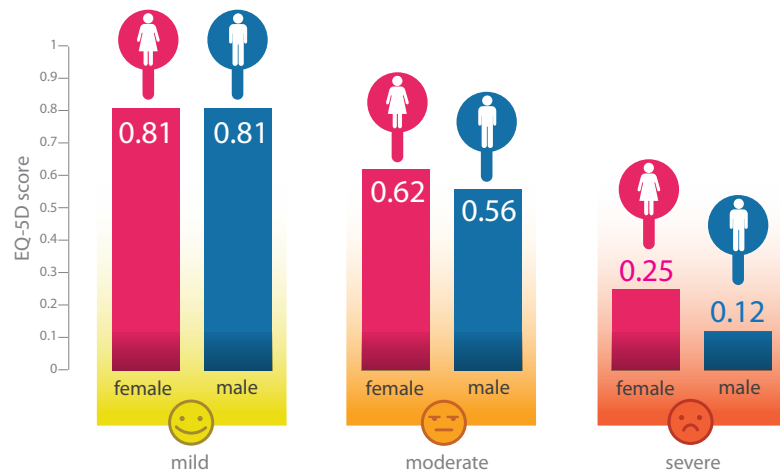


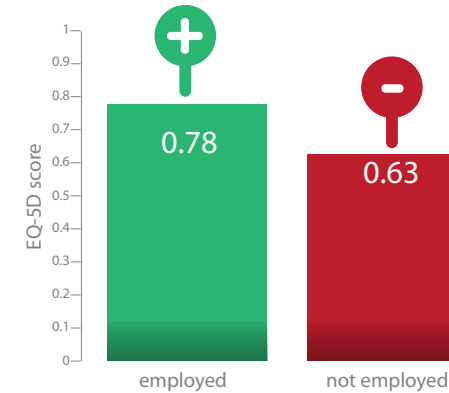
Figure 3b: EQ-5D scores by sex and MS severity



## Employment and Quality of Life

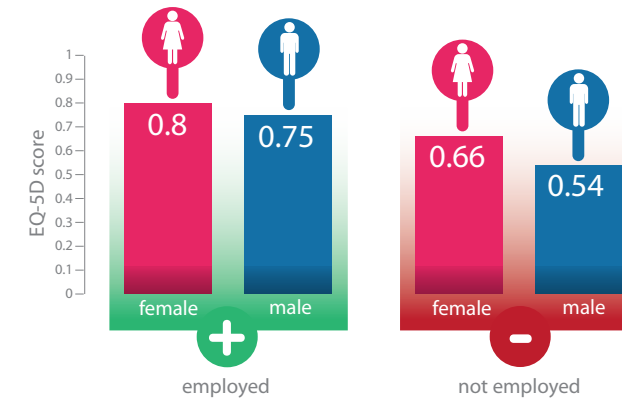
It is interesting to view the sample split by employment status. As we might expect, people with MS that are in employment have higher Quality Of Life scores than those not in employment (4a), for both men and women and for 'mild' and 'moderate' levels of disease activity.

Figure 4a: EQ-5D scores by employment status



**Employment status affects Quality of Life scores at every disease stage from mild to severe**

Figure 4b: EQ-5D scores, by sex, and employment status.



**These results indicate that people in employment have a higher Quality of Life on average – this is true across severity levels and show the importance of keeping people with MS in employment**



## Quality of Life is Higher in Relapsing-Remitting MS

As shown in Figure 5 below, health related Quality of Life varies across different forms of MS. Patients with the relapsing-remitting form of the disease are shown to have a significantly higher Quality of Life than those with a more progressed disease. By its nature, RRMS is associated with less neurological progression, though the unpredictability of relapses is a source of anxiety for people living with RRMS. The health related Quality of Life differences may also reflect the fact that no disease modifying treatments are currently available for primary or secondary progressive forms of MS, (although there are a number of positive clinical trials in this area), while people living with RRMS have more treatment options to actively manage their disease activity and progression.

Figure 5. EQ-5D-5L index scores by MS disease type

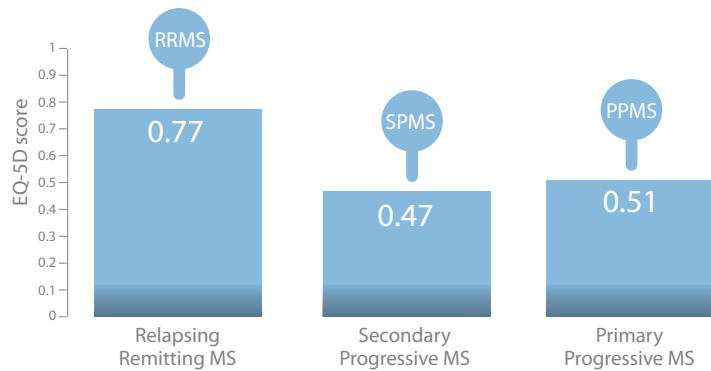
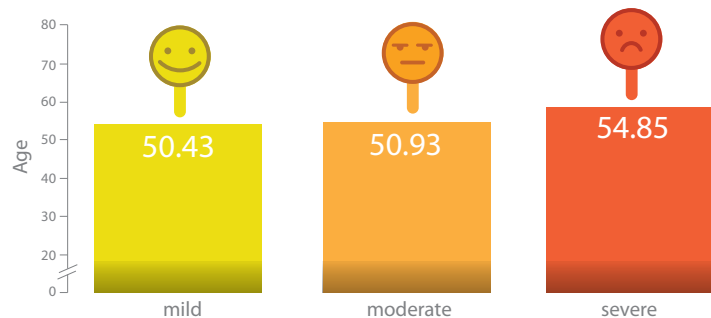


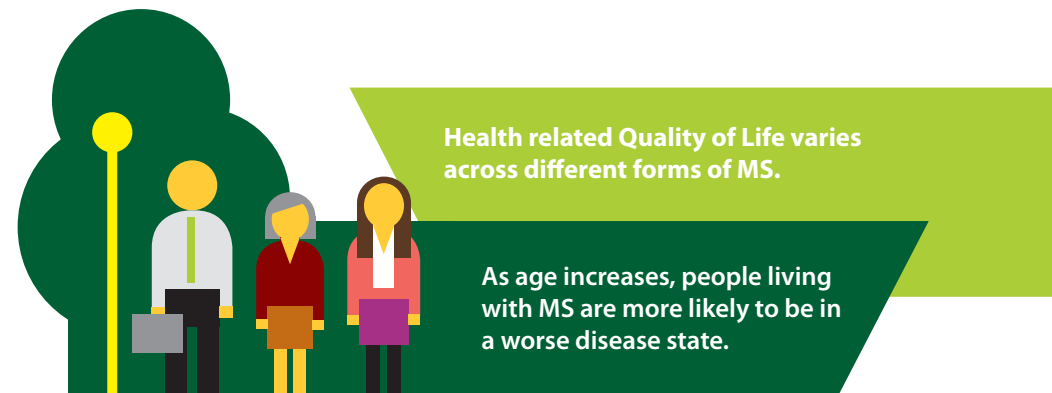
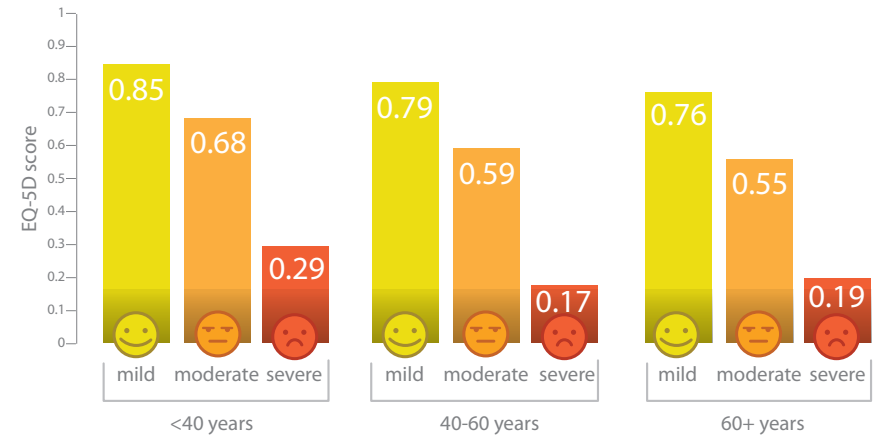
Figure 6 below shows the average age of people with different types of MS. The similarity in average ages indicates that disease progression is not a direct function of age and that people can be maintained in mild disease stages over time.

Figure 6: MS subjects' age and MS disease severity



Quality of Life decreases with age but disease severity is a bigger influence. Interestingly, there is substantial variation in the EQ-5D scores of MS patients in the 40-60 age range with 'moderate' disease severity as shown in Figure 7. It is also interesting to see that, in the 'severe' category, younger people with MS seem to fair better in terms of Quality of Life but there is a wide range of EQ-5D scores for people living with MS in the 40-60 age bracket, and 60+ years.

Figure 7. EQ-5D score by age category, and MS disease severity



## Key Factors that Affect Quality of Life in MS

When controlling for other factors, the large impact of disability severity on health related Quality of Life is unsurprisingly the most substantial influence on Quality of Life scores. The estimated scale of the impact is striking; where a progression from mild to moderate is associated with a 14% decrease in health related Quality of Life, and a progression to severe associated with a greater than 50% decrease in Quality of Life. The table below shows the key determinants of Quality of Life, arising from a multivariate regression analysis.

On average, controlling for other factors, Quality of Life is 5% lower for men compared to women.

Being in employment shows a positive effect on Quality of Life. This highlights the potential importance of people living with MS being able to remain in employment.

This analysis also provides for the first estimates of the effect of relapse activity; relapses have a negative effect on Quality of Life while a lack of relapses leads to a higher Quality of Life.

	Percentage (+ or -)
Age, reference category <40	
40-60	-7%
60+	-9%
Sex = male	-5%
Employed	+4%
Relapse Free	+3%
Informal Care	-9%
MS Severity, reference category = mild	
Moderate	-13%
Severe	-50%
Total sample	536

## Quality of Life in Multiple Sclerosis

### Case studies

#### Declan Groeger

##### Quality of Life in Multiple Sclerosis



##### How long have you had MS?

I was diagnosed in 1988 – you can do the math but it is a long time ago.

##### How would you describe your Quality of Life due to your MS?

Good.

##### In your life what are the top 3 most important things?

1. Family
2. Mental Capacity
3. Mobility - Independence

##### What would you like to do (or do more of) that you can't because of MS?

I would love to be able to swim again and I would also like to be able to look after our garden.

##### What, if anything, would make life with MS easier?

The knowledge that wherever I chose to visit was accessible.



#### Niamh McCarron

##### Quality of Life in Multiple Sclerosis



##### How long have you had MS?

I was diagnosed in June 2010, so almost 7 years.

##### How would you describe your Quality of Life due to your MS?

My Quality of Life, overall, is good. Thankfully, MS hasn't impacted on my mobility or cognitive function too much. I am still able to work, with some small adjustments, and have continued to progress along my chosen career path. I have a strong network of friends and family, who I socialise with regularly, and I am very active

in online communities. I don't know what it's like to be an adult without MS, but I think I am doing pretty well at getting on with life.

***In your life what are the top 3 most important things?***

**Peace of mind** – There is enough hustle and bustle and noise in the world today, so being able to live alongside your own thoughts and feelings is essential.

**Relationships** – My husband, family and friends. I am fiercely protective, possessive and proud of them all. They get me through the worst of times, and applaud me in the best of times.

**My health** – MS relapses are few and far between for now, but when they hit, I realise how precious my overall health is. We all have a responsibility to look after ourselves, and to be kind to ourselves.

***What would you like to do (or do more of) that you can't because of MS?***

MS makes me tired a lot. I miss being able to have a hectic few weeks, without suffering for it. Now I have to be prepared to spend some of my long-awaited weekends sleeping, instead of being out and about. I also need to know where the nearest toilet is at all times – I'd love to do less of that!

***What, if anything, would make life with MS easier?***

More information & understanding. MS is not a nice thing to have, but it's also not a death sentence. There is a lot of misinformation online and in the media, and we often hear the worst-case-scenario stories. A more balanced portrayal in the media would be great – stories about how a lot of us spend our days doing the normal boring stuff at work, or cleaning our houses, or doing the school run, might make things a little less frightening for the newly diagnosed and their families.

It frustrates me to hear about people with MS (or other illnesses) having to give up their jobs because of lack of understanding or provision from their employers. It baffles me that the effort to make small adjustments to the work place or working day is too much for some companies, so they instead opt to lose a key member of staff.

MS, like other invisible illnesses, can be hard to live with. People can be dismissive about conditions they can't see. A little bit of patience, support and understanding goes a long way in making someone feel valued and accepted. That's something we could all probably practice doing a bit more!

A more balanced portrayal in the media would be great – stories about how a lot of us spend our days doing the normal boring stuff at work, or cleaning our houses, or doing the school run, might make things a little less frightening for the newly diagnosed and their families.



**Maggs O'Riordan Wall**

***Quality of Life in Multiple Sclerosis***



Have actual themed parties with fun activities for people to get involved in, to forget about our disease for a while if you like with a room full of MSers all just 'getting' each other.

***How long have you had MS?***

Five years diagnosed but have it many years previous to diagnosis.

***How would you describe your Quality of Life due to your MS?***

Not great. I try to keep going but fatigue ruins my evenings mostly, I used to love getting dressed up and going out on nights out but now it's very rare. I used to love exercise, but now constant pins and needles occur after only a short stroll. And trying to recover after any kind of excursion, eg. weddings and what not, takes so so long! Sometimes a week!

***In your life what are the top 3 most important things?***

Family are a must. To appreciate the good days we get and make the very most of them, and making friends with the right kind of people, people with empathy, understanding, love, kindness and patience.

***What would you like to do (or do more of) that you can't because of MS?***

More socialising and more exercising.

***What, if anything, would make life with MS easier?***

Hmm good question. Having good friends would make it easier I'm sure. (I lost a lot of old friends but have made new, great ones!) Having 'travelling' MS events instead of always at cities, to have them in big towns so that people from little villages and parishes can travel to them without the hassle of a long and tiring journey, therefore bringing more people to MS events, making new friends with fellow MSers close to their locality. Setting up weekly sessions with psychologists for all MSers to help keep depression under control as this is one of the major and a could be deadly symptom of MS. Instead of having coffee mornings and what not, to have actual themed parties with fun activities for people to get involved in, to forget about our disease for a while if you like with a room full of MSers all just 'getting' each other.





## Quality of Life – My Story Declan Groeger



Quality of Life depends on one's position in the cycle of life and as I am fast approaching 60 years young mine will be different to that of a 30 year old. I believe that my life is not bad in fact I'd say that it varies between good and very good, especially when I consider that I have been living with Multiple Sclerosis (MS) for half of my life. Please don't misunderstand me when I say that my life is good; MS places a lot of restrictions on me. I have lost the ability to do many things that other people take for granted but I have discovered that I have other talents. I have come to accept my limitations and order my life accordingly.

I like going on holidays and love Spain in particular. Jean and I are just back from a weekend away in Co. Clare and are planning a

trip to Berlin later this year and other trips are in the planning phase. Holidays and outings need to be planned in advance but long term planning carries its own problems as I may not be able to do things on the scheduled day.

I go to the gym or the pool a number of times a week in an effort to stay as healthy and fit as possible and I love the social interaction there but believe me when I say that my efforts will never overwork any of the equipment. Exercise is good.

An absence of spontaneity has been part my life for many years so it doesn't bother me anymore I have adapted to the new me and I no longer have unrealistic expectations. Acceptance without resignation is good.

I still do 'stuff' about the house, neither as fast nor as good as I'd like but the jobs get done. I ration my energy; reserving as much as possible for things that I really enjoy. Playing with my grandson Jack is sitting on top the list of enjoyable things to do.

MS and time have taken their toll over the years and I now embrace Assistive Technology (AT): a wheelchair, rollator and automatic car with hand controls. Life is still good but different. I am strong in spite of MS not because of it.



Life is still good but different.  
I am strong in spite of MS not because of it.

## Conclusions

- Our findings show that people living with MS face impairment to their Quality of Life, particularly regarding pain, mobility and usual activities.
- While the economic burden of MS has been identified, this analysis creates a more detailed picture of the human burden of MS, using a standardised preference-based approach to the measurement of health related Quality of Life.
- Our findings estimate for the first time in Ireland the key factors determining Quality of Life for people living with MS, whether it be RRMS or SPMS and their relative influence.
- These findings may be of value to clinicians managing the care of people living with MS, as well as individuals and organisations that support and advocate for greater understanding and resources for people living with MS.
- Our findings in relation to the statistically significant relationship with employment prove actionable to policy makers. Similarly disease modifying drugs can reduce relapse in patients and keep disease activity at bay in some cases.

## Policy

### 1. Models of Care:

Implement the Model of Care for MS in the National Clinical Programme for Neurology, ensuring patients can get early diagnosis, appropriate treatment, regular monitoring to reduce disease activity and delay disease progression.

### 2. Employment:

Engage with MS Ireland to advance appropriate employment services that will enable and empower people living with MS in Ireland to gain or retain employment, and bring opportunities for people living with MS into line with our EU counterparts.



## Notes

### References

1. Societal Cost of MS in Ireland, MS Ireland 2016. [www.ms-society.ie](http://www.ms-society.ie)
2. Multiple Sclerosis and Employment, MS Ireland 2016. [www.ms-society.ie](http://www.ms-society.ie)
3. Quality of Life in MS. Under review 2017. For more details please contact Harriet Doig, MS Ireland.

### 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](http://www.ms-society.ie)

This document has been developed by Harriet Doig, Information, Advocacy and Research Officer with MS Ireland. MS Ireland would also like to thank the following for their input into the development of this document:

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