

# Quality of life for people with Multiple Sclerosis (MS) reported as being one third lower than the general population

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To mark World MS Day 2017, MS Ireland and Novartis have released research on the quality of life of people living with Multiple Sclerosis (MS) in Ireland. The research revealed that quality of life of people living with MS was 32% lower than for the general population and that men with MS have a 5% lower quality of life than women with MS.<sup>i</sup> The research was based on findings of a nationally representative study to understand the impact of MS on the 9 000 people living with the disease in Ireland.<sup>i</sup>

The respondents rated their experiences in the areas of mobility, self-care, usual activities, pain and discomfort and anxiety/depression.<sup>i</sup> Almost 80% of people with MS experienced pain and discomfort and was the highest of the variables measured.<sup>i</sup> 78% reported that they cannot complete activities of daily living such as getting dressed, cooking or washing.<sup>i</sup> 72% reported having issues with mobility.<sup>i</sup> 60% experienced anxiety and depression as a result of their MS.<sup>i</sup>

The research also reported that Ireland is below the rest of the EU in terms of the number of people working; 60% of people in the EU living with MS are at work whereas in Ireland just 43% work.<sup>i</sup> Being in employment was noted as having a significant impact on quality of life, further underlining health and wellbeing aspect of remaining in work for as long as possible.<sup>i</sup>

An associated report from MS Ireland revealed the economic burden of MS at €429 million per year with most of these costs sitting outside the healthcare system.<sup>i</sup> Of the identified €429 million cost, €134 million relates to healthcare costs with €214 million contributed by indirect costs such as time-off work and carers with the remaining €81 million cost associated with intangible costs an economic measure of the impact of MS on the person's quality of life.<sup>i</sup>

Multiple Sclerosis is a progressive disease with symptoms that include functional impairment and disabilities, visual disturbances, abnormal speech, swallowing disorders, fatigue, bladder and bowel problems as well as other sexual, mood and sensory impairment.<sup>i</sup> At the outset approximately 80% of people are diagnosed with relapsing remitting MS which means they have active periods when their symptoms flare-up.<sup>i</sup> Some of these people will progress to the secondary progressive stage of the disease where symptoms worsen more steadily over time.<sup>i</sup> 10 – 15% of people are diagnosed with primary progressive MS, which is characterised by slowly worsening symptoms from the start.<sup>i</sup> The report demonstrated that quality of life worsened significantly with periods of relapse and when the disease progresses.<sup>i</sup>

Commenting on the research findings, Professor Tim Lynch, Consultant Neurologist, Mater Hospital, Dublin said, "Quality of life is often overlooked in a person's care, but with a disease like MS, the impact on quality of life can be staggering and can compound clinical symptoms as well. What is clear is that early diagnosis leads

to earlier treatment which can help to delay progression of the disease. It is very clear that the longer we can keep people at the earlier stage of the disease, the better their quality of life will be.”

MS Ireland and Novartis have also rolled out a series of ‘MS Life Hacks’ which have been crowd sourced from people living with MS. The hacks are based on real-life experience that help to overcome some of the issues that people with MS face from buying clothes to cooking to practical ways to manage medication. See editors notes for a list of some of the MS Life Hacks or search #LifeWithMS on social media for more.

Speaking at the launch of the research, Ava Battles, CEO, MS Ireland said, “MS is generally diagnosed at a young age and weighs heavily on a person’s life. Family, work, social and personal life can all be impacted by the disease and for the first time we can now quantify this. We need everyone involved in the care of MS – people with MS and their loved ones, healthcare professionals, government – to work together to improve access to services, treatment and supports so we can improve life outcomes for people living with the disease. Along with Novartis, we have also unveiled our #LifeWithMS campaign featuring top tips for improving daily life when living with MS which we sourced directly from people living with the disease.”

Loretto Callaghan, Managing Director, Novartis Ireland said, “Novartis is again delighted to support MS Ireland’s mission to ‘inform, support, and care’ for people living with MS to have full lives. This research demonstrates the heavy impact of MS on a person’s quality of life. When we are healthy we take quality of life for granted but this is not the case for people living with a chronic disease such as MS. Novartis is committed to working with healthcare professionals, MS Ireland and patients to try to relieve some of the burden of living with MS.”

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