

First of its kind disease tracking and management resource launched for people with MS – SymTrac

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Research shows that substantial numbers of people with MS currently do not record important symptom changes, despite the potential impact on their disease.



- One in three people with MS do not keep any record of their symptoms in between medical appointments¹
- 45% have experienced a relapse but did not report it to their healthcare professional²
- Nearly 35% agreed that reporting relapses to their healthcare professional is extremely important³
- Approximately 85% of people with MS will experience relapses at some stage⁴
- Research commissioned to coincide with launch of new app, SymTrac, designed by people with MS and available for iPhone and Android devices

Monday 12th January, 2015: New research launched today has found that one in three people (31%) with multiple sclerosis (MS) in Ireland do not keep any record or notes on changes in their MS symptoms in between their medical appointments¹. This is despite the fact that these changes may indicate an MS relapse or attack which can be a sign disease progression.

Almost half of the respondents (45%) said that they have experienced a relapse in their symptoms but did not report it to their healthcare professional², yet nearly 35% agreed that reporting relapses to their healthcare professional is extremely important³.

Relapsing remitting MS (RRMS) is the most common form of multiple sclerosis. A relapse is defined as the

appearance of new symptoms, or the return of old symptoms, for a period of 24 hours or more – in the absence of a change in core body temperature or infection⁴. A relapse can also be known as a ‘flare up’ or ‘exacerbation’ in symptoms. Approximately 85% of people with MS will experience relapses at some stage during the course of their disease⁵.

The findings have been announced to coincide with the launch of SymTrac*, the first dedicated iPhone and Android device symptom tracker app for people with MS. The free app has been designed by people with MS and developed in conjunction with Novartis. SymTrac helps people with MS to take more control of their health by monitoring changes in their condition more effectively.

The online research** was conducted among MS Ireland’s members to investigate how people with MS keep track of their condition in between appointments with their healthcare professional, and to encourage people with MS to avail of new resources which can assist with tracking the symptoms of their MS and their overall wellbeing.

SymTrac records symptoms as well as general health and wellness information, allowing users to build a comprehensive picture of how they feel over a period of time. The app creates easy-to-read charts which can be stored and shown to healthcare professionals during medical consultations. By recording and keeping all of this key information in one place, people with MS can chart their condition between appointments, and make the most out of their vital consultation time.

Dr. Killian O’Rourke commented on the launch of SymTrac and the importance of relapse recording. “An increase in relapses can mean that a person with MS might require a different approach to their treatment. It is incredibly important that people with MS record any changes they notice in their condition so that they can discuss those changes with their healthcare professional and informed decisions can be made about managing their MS most appropriately. SymTrac will be a really helpful way of keeping this information in one place, and helping people to remember everything they want to discuss during their appointment, ensuring they get the most from their appointment,” he said.

A new information booklet for people with MS has also been produced as an additional educational resource. Understanding Relapse in Multiple Sclerosis - A guide for people with MS and their families is available by contacting MS Ireland and can be downloaded in PDF format from MS Ireland’s website. The booklet gives detailed advice on how to manage a relapse and what to expect once one occurs. The guide encourages people to contact their MS nurse or specialist as soon as they experience a relapse.

Commenting on the research and the importance of these new resources, Ava Battles, Chief Executive, Multiple Sclerosis Ireland said, “The findings of the research have really highlighted how our members feel about reporting their relapses to their nurse or doctor. As an organisation we need to encourage people with MS to realise how important it is to take control of their own personal health by monitoring, recording and reporting changes in their condition. The new app and materials will be really beneficial to our members, helping them to learn more about reporting and recording relapses and keep track of their MS in one convenient place.”

Speaking about the interactive and educational materials, Loretto Callaghan, Managing Director, Novartis Ireland said, “We are delighted to work with MS Ireland on the development of these important resources which we hope will help people with MS play a more active role in monitoring their health. The information recorded on Symtrac can help to guide people with MS and their healthcare professionals with important decisions regarding their treatment and management of their MS.”

For more information on SymTrac and the Understanding Relapse in Multiple Sclerosis booklet please visit

References:

1. MS Relapse Survey, December 2014. Question 11. 30.56% said they never keep a record of their symptoms between appointments which may be related to a relapse. N=216
2. MS Relapse Survey, December 2014. Question 9 (45.37% answered no). N=216.
3. MS Relapse Survey, December 2014. Question 17 (34.74% answered 'extremely important'). N=190.
4. MS Ireland's website: <http://www.ms-society.ie/pages/living-with-ms/what-is-ms/first-questions>
5. Burgess: Multiple Sclerosis Theory and Practice for Nurses. 2002

* SymTrac is a free app which records symptoms of MS and general health and wellness information, including what part of the body is affected and the severity of each symptom recorded. It allows users to build a comprehensive picture of how they feel over a long period of time, and creates easy-to-read charts which can be stored and shown to healthcare professionals during medical consultations. Symtrac can be downloaded for free from the iTunes App Store and is compatible with iPhone, iPod Touch and iPad and requires iOS 7.0 or later. An android version is also available from Google Play.

**The online research was conducted via MS Ireland's website and encouraged users to complete a survey regarding their MS and relapse recording. 353 respondents filled in the questionnaire, but some of those people skipped some questions so the majority of questions were answered by 216 people with MS

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