

Information for patients from JNNP

How long do the benefits seen in studies of MS drugs last?

What do we know already?

Much of the evidence about what treatments work for multiple sclerosis (MS) comes from randomised controlled trials. These studies compare a treatment either with a dummy pill (a placebo), or with another treatment, to see which treatment improves the symptoms of MS.

Many of the trials that have looked at what MS treatments work have been done over two or three years. But we need results taken over a longer time to learn more about the benefits of treatments over the long term. This is especially important for conditions like MS, which can progress over many years.

A treatment for a condition like MS might change how the disease progresses but not affect people's outcome, especially over many years. So it's also important to know if the results seen in studies of MS treatments mean that people with MS will see improvements in their symptoms over the long term. It would be useful for researchers, too, to be able to predict who might see long-term benefits from treatment, based on what happens to them during the trial period.

Researchers got in touch with 260 people with MS who originally took part in a trial of a treatment for MS called interferon beta, compared against a dummy pill, 16 years after the study ended. They were asked detailed questions about their health, how their MS had progressed and affected them, and how well they were now able to function in their daily lives.

What does the new study say?

At the beginning of the study people rated their own level of disability caused by their MS, as measured by a scale called the Expanded Disability Status Scale (EDSS). The higher a person scores on the scale, the more affected by disability they are. A score of six or more is said to be a significant enough disability to affect people's ability to walk and perform daily tasks.

At the beginning of the study, people scored an average EDSS score of 3. By the end of the two-year trial the average disability score had only increased 0.05. However, the disability score increased much more, to 5.17 points, by the end of the 16-year follow-up study.

At the end of the follow-up study nearly one person in two had reached an EDSS score of 6.

Using statistics, the researchers were able to calculate that the original EDSS score over the course of the trial was a better way to predict how much people would be affected by disability later on in life. How much people's EDSS score changed was a good way to predict how much people would be affected, both physically and in their ability to think clearly.

How reliable are the findings?

The original study was a randomised controlled trial comparing people who were given either different MS treatments or a dummy pill. In these trials people do not know what treatment they are being given, and this usually makes the results more reliable. But during the follow-up study, people were encouraged to take the active treatment, which may have affected their level of disability and the results.

What does this mean for me?

The researchers say this is the first study to look at the short-term results seen in people with MS who take part in drug trials and use them to predict how well people did over the long term. This should mean that, in future, researchers are able to measure the long-term benefits of MS treatments more accurately.

What should I do now?

If you have multiple sclerosis (MS), the nerves in your brain and spinal cord become damaged over time and may stop working properly. There's no cure at present but treatments can improve your symptoms, slow down the disease, and help you keep living a full life. It can be difficult to say for certain what course your MS will take, and this can make it hard to know what treatments are best for you. Studies like this will build the evidence researchers can use to try and predict how MS treatments will work over the long term.

From: Goodin DS, Traboulsee A, Knappertz V, et al. Relationship between early clinical characteristics and long term disability outcomes: 16 year cohort study (follow-up) of the pivotal interferon b-1b trial in multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2012;**83**:282–287. <http://jnnp.bmj.com/content/83/3/282.full>

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