

The results of the 2011 MSAC Oral Medication Survey are in.

Thank you to the 556 people who responded to the survey.

This is a snapshot of the results. A full report with all the details is also on the MSAC website

Who took part in the survey?

Most of the 556 respondents were people with MS (94%), and the other 6% were carers, family and friends of people with MS or healthcare workers.

Overall, the survey respondents were a fairly representative sample of people living with MS in Australia in terms of gender, age, type of MS and where they live in Australia.

- Most of the respondents were women (79%) and 21% were men.
- The age of respondents (including those with no MS) were:
 - 41-65 years old (60%)
 - 20-40 years old (34%)
 - + 65 years old (6%)
 - Less than 20 years old (less than 0.5%).
- People had been diagnosed with MS for an average of 8.6 years (range <1 to 56 years)
- Most people with MS had relapsing remitting MS
 - relapsing remitting MS (77%),
 - secondary progressive MS (11%)
 - primary progressive and 21 (8%)
 - another type of MS or unsure of the type (4%)
- Most of the respondents live in a capital city
 - Capital city (68%)
 - Regional, rural or remote area (32%).

Have you heard about oral medications for treating MS?

Overall, 84% of people who responded had heard about oral medications for treating MS.

The most common places for people to have learned about oral treatments are:

1. a neurologist
2. an MS Australia publication such as *In Touch*
3. the MS Australia website
4. a friend
5. a website other than the MS Australia website.

How important is it to you that oral medications are available in Australia to treat MS?

Most of the respondents (90%) feel that it is either moderately or extremely important that oral MS treatments should be available in Australia.

Of the 10% who ticked “not very important, “not at all important” or “unsure” most felt that they did not have enough information to make an informed decision. Others believe their current treatment (drug, angioplasty, diet) is superior to currently available oral MS treatments.

Several respondents expressed concerns about the potential toxicity of oral treatments with some wanting to see the drugs in widespread use before they would consider trying them.

How important is each of the following factors when considering whether an oral MS treatment may be appropriate for you or someone you know?

Respondents rated the importance of seven factors on a five-point scale ranging from “extremely important” to “not at all important”. Three factors stood out with almost everyone selecting “extremely important” or “moderately important”:

1. The EFFECTIVENESS of the treatment
2. The SAFETY of the treatment (note that how extensively the treatment has been used was also thought to be important by the majority of respondents)
3. The COST TO THE PATIENT of the treatment

How useful would it be if MS Australia were able to offer each of the following types of support for people considering or trying an oral medication to treat MS?

All types of support listed were rated highly by most people, but in general, *information* was seen as the most useful thing MSL can provide to clients, with both information on the website and information in MSL publications seen as “extremely useful” by the majority of respondents.

Group sessions to learn about a particular treatment were rated least highly, but 34% of respondents rated these as “extremely useful”.

Are there other types of support you would like MSL to provide?

A full list of all comments provided has been sent to the Board of MSL exactly as people provided them. Below is a summary of the top five responses.

1. Unbiased information (free from the influence of pharmaceutical company)
2. Detailed, up-to-date information to assist people making choices about MS treatments, including comparative information on side effects and the effectiveness of different treatments
3. Support for GPs
4. Support for family members
5. Plain English summaries of the latest scientific information and studies

The recurring theme was that people want INFORMATION that is accurate, up to date, free from pharmaceutical company influence and accessible.