



2012

A blossoming of potential across NSW and ACT!

The only goal of MND NSW is to be of value to its members. This can take the form of practical assistance; moral support; much needed respite; a sense of community; or the unity in numbers necessary for effective action. In all of these efforts, there is no better measure of our success or progress than in terms of member satisfaction.



So it is with great pride that I now share with you the results of our MND NSW Membership Satisfaction Survey 2012. Almost without exception, we were rated more highly this year by our members than we were in 2009. That means our most important critics think that we are performing better! In fact, when our members rated us across 24 criteria using a satisfaction scale with 1 being "very poor" and 5 being "very good", we did not rate lower than a 4 in any criteria.

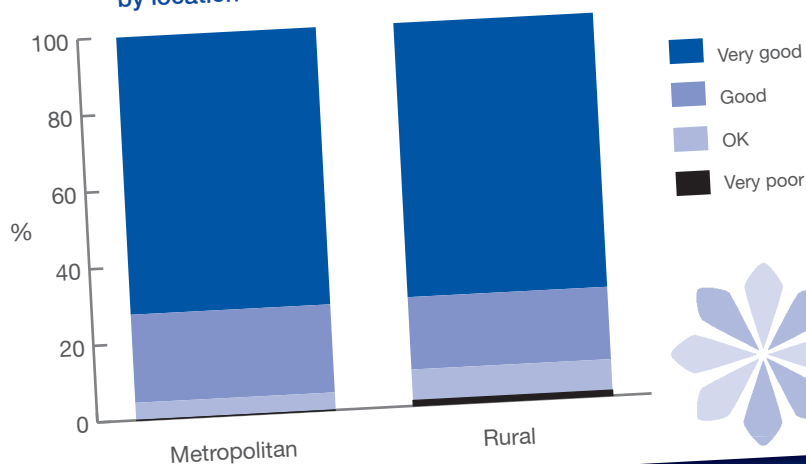
Does this mean that the survey was nothing but a self-congratulatory pat on the back? I sincerely don't believe so. By providing open-ended questions and soliciting member feedback, we use these surveys to identify areas where our members would like to see improvement. These areas become our focus in the following years.

For example, we have worked hard over the past few years to improve our regional services. We have increased our RA visits to regional areas, and plan to increase the number of visits yet again. We have made new educational programs available in regional areas for service providers, members, and families, including carers programs, information days, and a brand new program called MND Aware that includes a free online training program for health and community care professionals, as well as MND Aware Face to Face training days. We are proud to say that in this year's survey, our regional members are as satisfied with our services as our metropolitan members are.

So, please let us take this opportunity to celebrate what has been accomplished, as rated by our members. Let's take a look at how you find our services now, and where you're steering us for the future.

Graham Opie
Chief Executive Officer

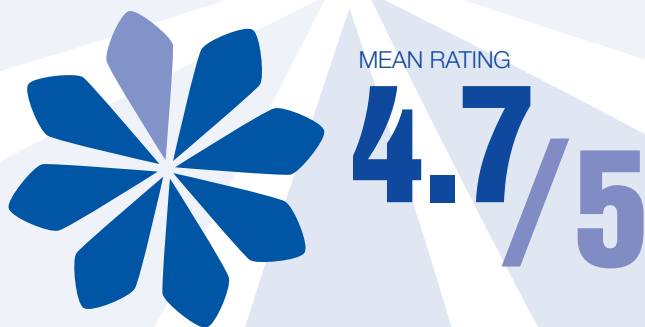
**Satisfaction with overall support and information provided -
by location 2012**



What you're saying:

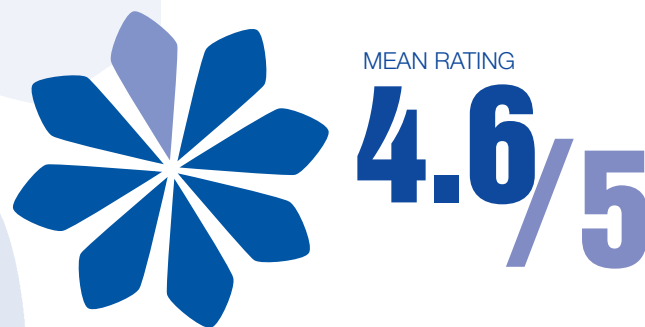
Telephone and email support

“I spoke to [MND support line staff], whose compassion and understanding impressed me and gave me confidence to accept this disease. So from being quite depressed, I was immediately on a high, knowing that we were not alone in coping with MND.”



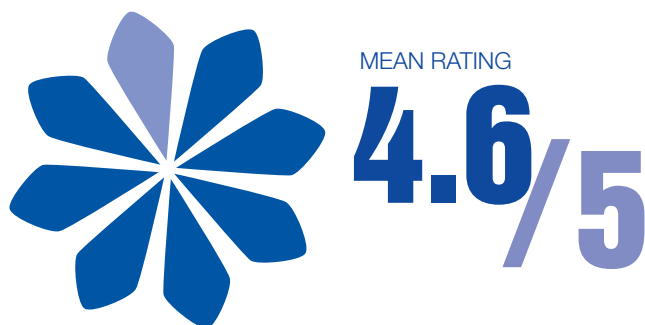
Written information

“The information, from the initial pack to all the newsletters and research summaries is most encouraging. It is good to know that so much is done to find out the cause of MND and in time, a cure.”



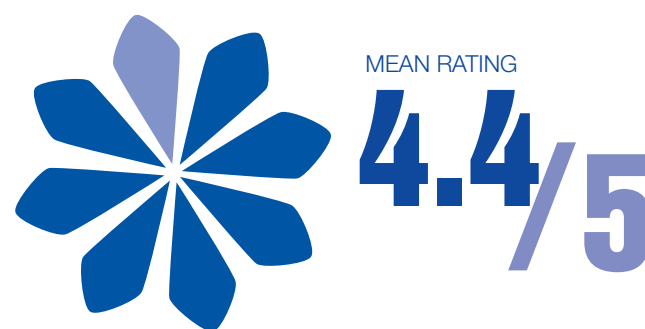
Regional advisors (RAs)

“My regional advisor contacted me and as I could not attend her morning tea, she travelled the 40kms extra to visit me and explain her role. I like her friendly manner and the value of the information she has given. I regard her as a friend.”



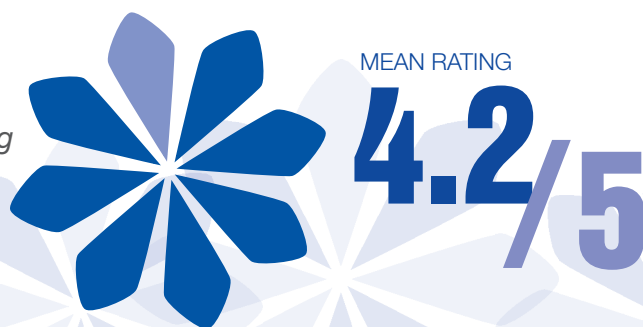
Educational programs and information sessions

“Education programs are excellent ways to learn and share. Highly recommend attending at least one program.”



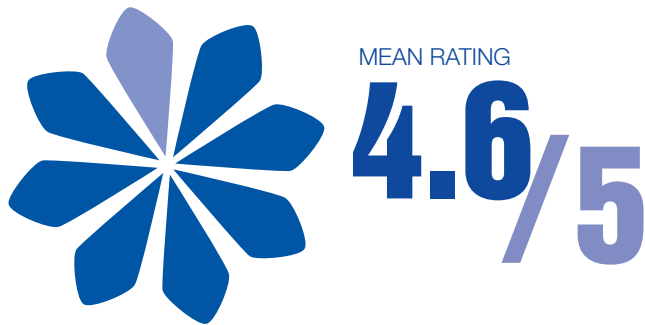
Support groups

“We were initially a little reluctant about the support group, but it has been a good way of linking with other people in the local community with MND. It has also started to be a good way of information sharing which is beneficial, as everyone is navigating different equipment/services.”



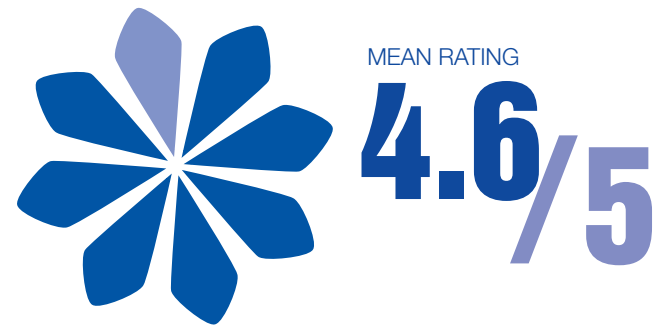
Equipment pool—quality

“Everyone is great and helpful, and equipment delivered quickly and always in good condition.””



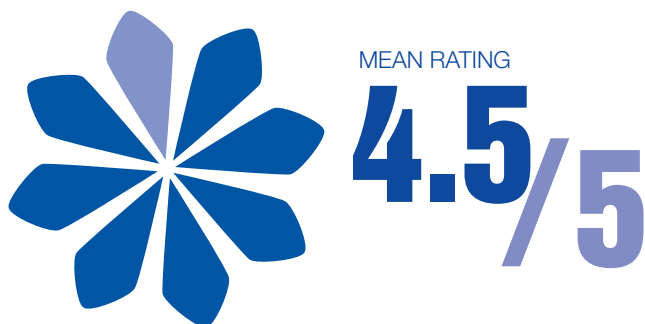
Equipment pool—availability

“Without the equipment pool, [we] wouldn't be able to stay at home. We are very grateful.””



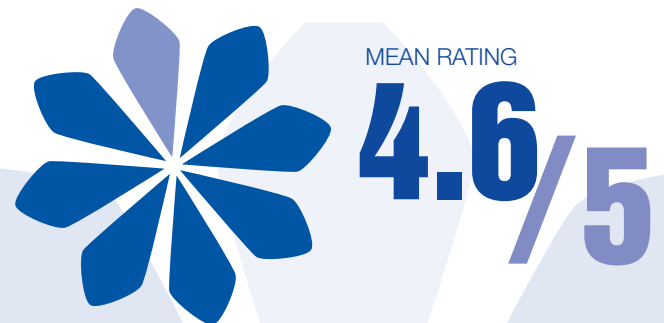
Support for carers

“As a wife and carer, who deals with a frail, stubborn husband, I have to say [MND NSW] were excellent when dealing with my anger, anxiety, and many questions.””



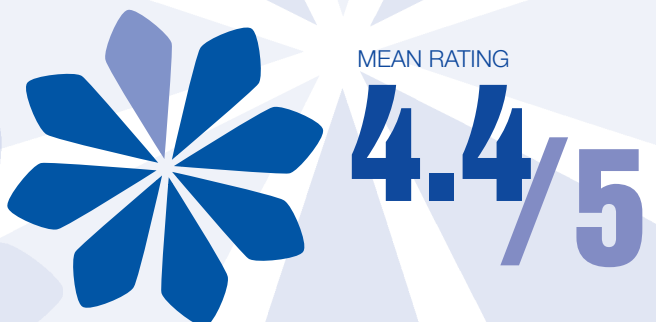
Overall support and information

“I cannot imagine how I could have gotten through the past 5 years without the MND Association.””



Are we good enough to recommend?

“Definitely I would recommend anyone, sufferers or families, to contact MND NSW. As the disease is rare, most people know nothing about it and it is easy to refer them to the website.””



But we still have work to do!

Although it was rewarding to see that in general our services are highly rated by our members—for which we have to thank our staff, our donors, and our dedicated volunteers—the survey did highlight some key areas for improvement.

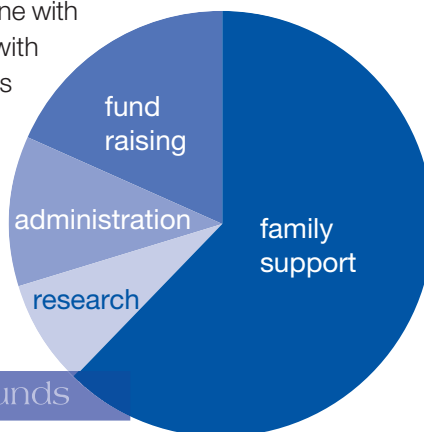
The restriction of the equipment pool to short term loans is frustrating and disappointing for some members. To make long-term equipment loans available to those who need them, we are working closely with EnableNSW, the State government's equipment pool, to make their equipment more accessible to our members.

Although regional members are as satisfied overall as Sydney-siders, there are members who still feel that, because of geography, they are not getting the support they need. To help address this, we have recruited an additional regional advisor for Western Sydney/Western NSW.

And, moving our focus from support to advocacy, members want to see more work towards raising awareness about MND, and more information about new therapies and drug trials. We will continue to raise awareness of MND through our MND Aware Face to Face training for health and community care professionals. This training will be held in at least 24 locations around the State and will help give health and community care professionals the knowledge they need to provide the best possible care to people with MND. We are also happy to report that in the immediate future, we will be collaborating with a pharmaceutical company to obtain and disperse information on the dexamipexole clinical trial.

You can help us in our efforts. Anything you can contribute financially would be greatly appreciated. Please go to "Donate" at www.mndnsw.asn.au to make a secure donation online with a credit card, or download a form to fill and send with your cheque in the mail. Of course, you can always phone us at 02 8877 0999, if you prefer. If you would like to make a gift to MND NSW in your will, please contact David Dubin on 02 8877 0917, or email davidd@mndnsw.asn.au. We would love you to join our Blue Cornflower Society — invaluable benefactors who support the work of MND NSW.

Where we spend our funds



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