



What do you think about the work done by the ME Association?

A report on the outcomes of patient surveys created by the ME Association and posted online for members and non-members – November 2015

“If it wasn’t for the ME Association I don’t think I would have been able to move from being very severely ill to where I am today.”

“The MEA has been there since I first became ill and given support when all else has failed. It’s continuing presence is very important to me.”

“Members of the charity have been very quick to help me with problems and especially Dr Shepherd, as he is so busy and trying to do so much despite his own poor health. I’m very grateful to all the team.”

“I like and trust that many people working for the MEA have firsthand knowledge and experience of ME.”

Introduction

We received a great number of comments from the 159 members (and 107 non-members) who took part in the recent online surveys that sought your views about the ME Association.

Both surveys enabled us to discover; why you joined as a member, or remained a non-member, what you specifically liked, or did not like, whether or not we had lived up to your expectations, how well we were performing as a charity for those with this devastating illness and how we were doing in supporting you, in lobbying for change, and in the vital area of research.

Your answers have helped us to see what we are doing well and where we need to do better and will form part of our ongoing strategic review.

Demographics

The initial questions helped us obtain demographic information which revealed that:

- 92% of members (85% of responding non-members) had a diagnosis of ME/CFS and 3% of members (7% of responding non-members) were carers
- 77% of members (79%) were female and 23% of members (21%) were male
- 86% of members (58%) were aged between 40 and 80 with 37% of members (8%) aged over 61
- 62% of members (48%) had had the diagnosis for longer than 11 years with 29% of members (25%) diagnosed more than 21 years ago

When we asked what affect the illness had on overall health, 6% of members (2%) indicated it had a mild affect, 39% (35%) a moderate affect, 43% (49%) a severe affect and 8% (7%) a very severe affect.

Reasons for joining

Our next question asked about the main reasons for joining the MEA. Members could choose from as many of the examples given as they felt applied or provide their own. The top 5 reasons were:

1. I wanted a continuing source of reliable support and information (82%)
2. I agreed with what I felt was the MEA ethos i.e. that ME is a real and physical disease (76%)
3. I wanted to belong to a charity that provided support, lobbying and biomedical research (61%)
4. I wanted to be part of a community which ensured I no longer felt isolated and alone (57%)
5. I wanted to contribute financially to the work of the MEA (48%)

Value for money, Facebook and Twitter, and referrals from GPs or NHS specialist service providers were among the lowest chosen reasons for joining.

“I found the information leaflets were excellent on dealing with work and benefit issues.”

“I was desperate for information that would give me good advice to help in any recovery I might make and found the magazine offered the best hope.”

Reasons for not joining

We asked non-members what reasons might have influenced any decision not to join the MEA and again we provided a list of possibilities from which they could choose, or they could provide their own. The top 5 chosen reasons were:

1. I cannot afford the annual membership subscription (25%)
2. I feel I can benefit from the MEA without becoming a member (21%)
3. I did not know the MEA offered membership (16%)
4. I am a member of another charity that does similar work (15%)
5. I did not think that becoming a member was all that important to the work the MEA does (13%)

Some of those answering the non-member survey were not resident in the UK and felt the MEA did not cater to their specific needs. Others felt the MEA did not cater sufficiently to the needs of the more severely affected or had concerns with regards to the MEAs use of nomenclature and 'encephalopathy'. Yet others seemed to have confused the MEA with other UK charities, and some indicated they had not been aware of the MEA but would be joining soon.

"There is no work done for patients with severe ME that I can see. A lot of reference to what people with severe ME go through so a lot of talk and use of severe patients, but nothing concrete done."

"I follow you on Facebook but due to the severity of my M.E. I do not spend long at the P.C. I kinda like being able to keep up with things in this way, and never have I been made to feel pressured into joining which can only be a good thing."

"I am just a bit unsure what being a member would offer. I find most of what happens is a vehicle for those on benefits and a platform to complain. I actually find it quite negative. I have worked hard to stay in my job and I don't think this advice is offered. More positivity would be refreshing. I love some of the work that happens but I find it's just got a negative vibe all the time."

"Only just became aware of you really and will be joining soon."

What you liked...

Asking if there was something that was really liked about the MEA gave responders the opportunity to highlight things about the charity that really stood out. 85% of members (63% of non-members) indicated there was something they really liked and we received 183 comments in total providing us with some specific examples. You liked that the MEA was:

- Friendly and responsive to enquiries and to sharing the latest news and research.
- Providing kind, considerate and sensible advice and a haven from isolation.

- Punching above its' weight in terms of quality output compared to its size.
- Bold and robust yet professional in its criticism of the PACE Trial, the NICE guideline, and psycho-social theories of illness perpetuation.
- Providing up-to-date, reliable and relevant information on its website, in its publications, in ME Essential magazine, and on its social media.
- Leading the fight against the psycho-social view and advocating the need for more biomedical research.
- Doing exactly what it said it would by providing support, actively lobbying for recognition and improvements and funding biomedical research.

“It stops me from feeling so alone. It is a very strong advocate for patients.”

“I really appreciate the extraordinary amount of work and effort that each of you dedicates to supporting our community.”

“I like that it has regular medical input from Dr Shepherd, who seems like a reliable doctor with a thorough knowledge of ME and ongoing interest in current research.”

“The ME Association makes me feel less isolated. I believe that ME is real and physical and I like that the MEA is wholeheartedly behind research to prove this.”

“I like most of all that you are consistent in your beliefs about this illness and vigilant on our behalf about negative media coverage...”

“It sticks to its guns about ME being a physical illness, not psychological, and continually fights against the prevailing NICE guideline re: CBT and GET.”

“It is a wonderful community of people who care and understand. There is much support available, and ME Essential is super.”

...and didn't like

Asking if there was something you didn't really like about the MEA resulted in 25% of members responding 'Yes' and 67% 'No', with 8% uncertain (36%, 43% and 21% of non-members). We received 71 comments in total providing us with specific examples. You didn't like that the MEA was:

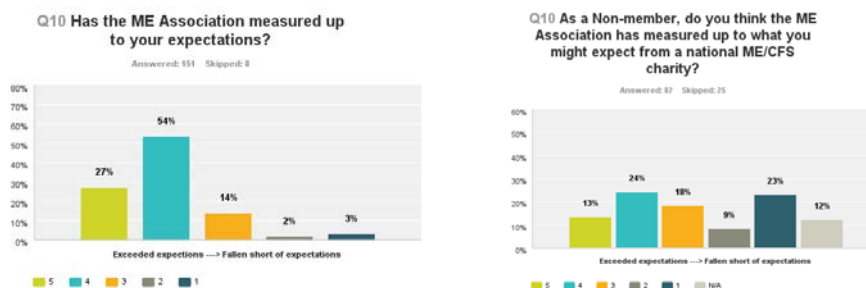
- Not paying sufficient attention to the more severe end of the illness spectrum and not actively trying to help those most severely affected.
- Increasingly using the internet because your illness often meant you could not use a computer or hand-held device, although you could appreciate the reasons behind it.
- Too quick to react to criticism of itself on social media.
- Offering very little extra to members when it seemed that non-members were benefitted just as much.

- Charging a membership fee even to those who were struggling economically.
- Spending money on certain research projects you didn't agree with.
- Seemingly so reliant on Dr Shepherd, and you felt it should actively seek more experts to help share the load and enable it to do more.
- Featuring complex articles or research that you didn't understand but might be important.
- Featuring articles about those who were able to achieve more and that you felt might reflect badly on those who could not.
- Not featuring enough articles about those who are able to continue working etc. despite having this illness and/or more positive stories.
- Unable to do more to make its' campaigns bigger and reach a much larger audience or fund larger biomedical research studies.
- Not advocating clearly enough for "myalgic encephalomyelitis" and you felt it should be unequivocal in this regard despite all the uncertainty and arguments against use of this name.
- Seemingly old-fashioned in its appearance restricting its appeal.

Performance

Overall vs. expectations

We began this section by asking if the MEA had measured up to your overall expectations. The chart below on the left shows how our members responded to the question and the one on the right indicates how non-members responded to a slightly different but similar question:



It was very pleasing to note that 95% of members felt the MEA had met or exceeded their expectations, and that even among non-members there were 55% who felt similarly (not allowing for those who indicated the question was not applicable).

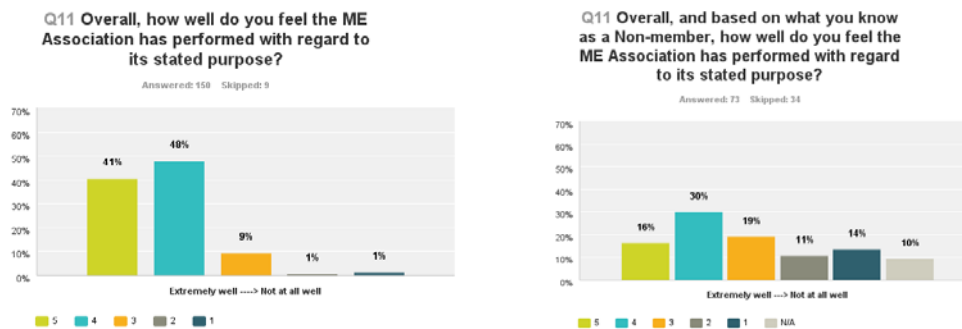
Comments were invited from those respondents who felt performance had 'fallen short of expectations' i.e. 3% of members and 23% of non-members. However, the 22 comments we received did not give examples of where the MEA had underperformed, but either repeated previous general concerns or were in fact suggestions of ways to improve, such as:

- Hosting an online forum
- Offering specialised support for local groups around the UK
- Including – on featured controversial news items – an MEA position statement

- Taking more care to feature the severely ill and the particular issues they face
- Listening more to patients

Vs. stated purpose

Next we asked you to rate performance in relation to The ME Association’s stated purpose, which is: to offer relief to persons of all ages with ME/CFS through the provision of information, and to further education in all aspects of the illness, and to support research into the illness including the making of grants and to publish the useful results of that research.



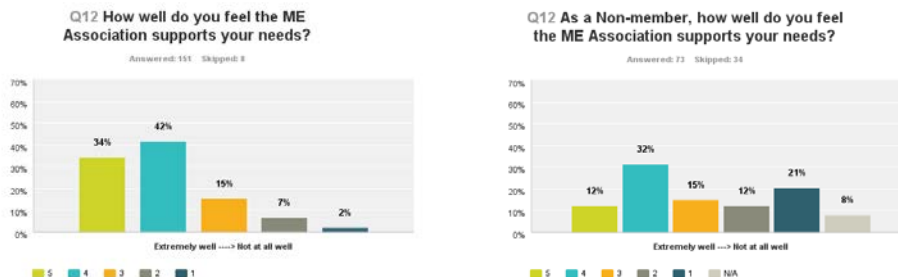
It was very pleasing to note that 98% of members felt the MEA had performed well or extremely well in this regard, and that 65% of non-members felt similarly. Comments were invited only where people answered, ‘Not at all well’, but many of the 20 comments we received were positive endorsements.

However, a couple of people clearly felt the MEA had underperformed and expressed concern about the lack of specific representation for the more severely affected and over use or lack of use of specific nomenclature. There were also a couple of non-members clearly confusing the MEA with another UK charity in their critique, but generally the comments received were indicative of people wishing for more resources to better enable existing actions to have a greater impact or for actions to be taken that would address more personal needs.

“I think the MEA does well on the whole, many people from the severe community don’t agree, but I’m more understanding that you can’t do everything and get everything spot on. So although I feel there is work to be done, I’m glad for the work MEA does, which has supported me in the past with publications that have helped my doctors treat me better, and for that I’m very grateful.”

Vs. support

We next grouped the main activities the MEA is involved with under the headings, Support, Lobbying, and Research and asked both members and non-members the same question (recognising that the MEA may well mean different things to each group of individuals):



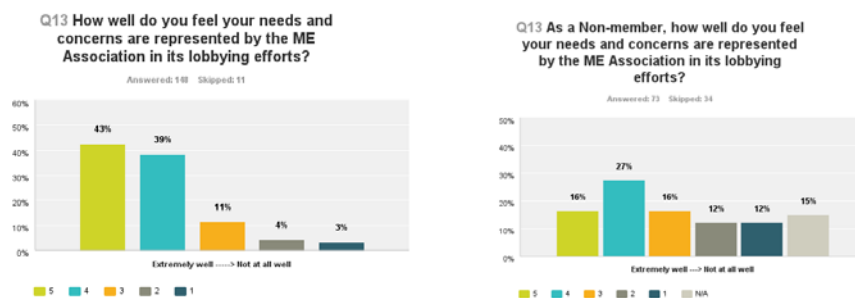
Support: 91% of members (59% of non-members) felt the MEA supported their needs well or extremely well. The majority of the 27 comments we received were again either complementary or carried suggestions about things we might do to enhance the support we already provide and not really examples of where the MEA had not done well.

However, and in addition to some of the things already mentioned above, individuals indicated that we should:

- Pay more attention to the needs of the older patient
- Feature progressive ME
- Be more aware of people in Scotland
- Provide better support for local groups

“I find my treatment plan is completely at odds with what I see at the MEA site. I’m doing GET, it’s non-prescriptive and tailored to my energy levels, and because it is GET I feel like a pariah on the site.”

Vs. lobbying



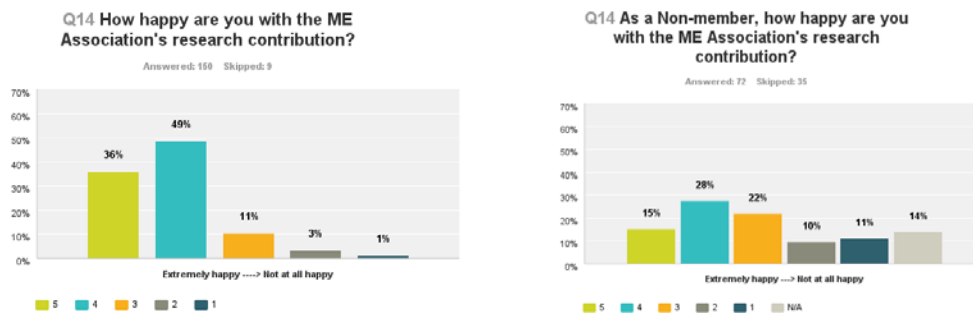
Lobbying: 93% of members (59% of non-members) felt the MEA represented their needs and concerns well or very well in regard to its lobbying efforts. We received 29 comments in total some of which were again complementary while others reflected perhaps a lack of knowledge about the things we had achieved.

We had invited comments only from those who felt the MEA had performed ‘Not at all well’, and these individuals felt we perhaps needed to:

- Be more controversial to reach a larger audience
- Focus solely on “myalgic encephalomyelitis”
- Feature the severely ill more often
- Shift efforts to include lobbying business

“Very well generally – exceptional even given the resources, but at the end of the day I am still left struggling against DWP, employers and insurers, and sceptical doctors, alone.”

Vs. research



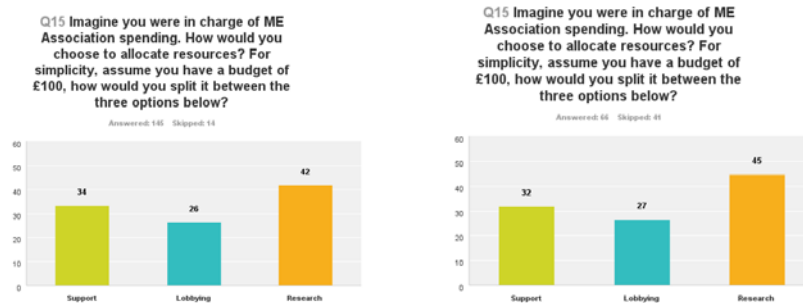
Research: 96% of members (65% of non-members) indicated they were happy or extremely happy with the MEA research contribution. The MEA funds research studies via The Ramsay Research Fund and some of the 31 comments reflected that we had clearly not done enough to keep you informed of the work done and that is continuing in this regard or explained clearly enough how this fund works in relation to our other activities.

Again, we asked for comments only from those who felt they were ‘not at all happy’, but received complementary comments as well including recognition for the Biobank funding and appreciation that we could only do so much. Other comments reflected the general disappointment many of you feel with research progress in general and that is outside of our efforts, whilst several felt we should focus on larger studies and/or replication attempts rather than small, pilot efforts and yet others queried our position on Rituximab and the planned UK clinical trial.

“The MEA does an amazing job but very little research has been achieved compared to many other illnesses but this is due to a lack of government investment as your efforts on our behalf are outstanding.”

Spending

When we asked you to imagine you were in charge of MEA spending, and to allocate £100 across the three main areas of activity i.e. support, lobbying and research, it was very interesting to observe the total results and compare member responses (below on the left) to those from non-members (below on the right):



Taken together the results would indicate that you place more value on Research, followed by Support, and then Lobbying, but the vast majority of you saw value in the three areas and chose to spread your spend within each of them. Only, for example, did 2 members and 2 non-members choose to place 100% of their allocated spend in Research. Others might have chosen to spend, for example, 10% on Support and more on Lobbying and Research than is shown in the totals above, but there was at least some value acknowledged in each of the areas being pursued by the MEA collectively.

Unique

45% of members (28% of non-members) answering this question felt there was something unique about the MEA and examples from the 94 comments we received included: Dr Shepherd and our friendly and experienced team, ME Connect helpline and our volunteers, our professionalism, all-encompassing approach, range of publications, credibility, consistency, knowledge and our willingness to collaborate with others when necessary.

Also, the focus we have on this being a physical disease, on biomedical research and the clear rejection of a psycho-social explanation, as well as the effective use of patient evidence in our lobbying efforts. And, that we listen.

“Dr Shepherd. Sorry to name names, but he really has consistently been at the forefront of the ME scene and has held his own, without hysterics, against negative thinkers and charlatans.”

“It’s authoritative. Charles Shepherd should take a lot of credit for this on the medical side – he’s top notch.”

“Support and speed of response. Knowledge.”

“The most established and the most credible. The least flaky (!)”

“It has a sense of really caring for individuals rather than just the disease.”

“It’s empowerment of members.” “It listens to its members.”

“It allows people to make up their own minds on anything in the press.”

“It’s the big one, the main one. The one I refer people to.”

Donations to the ME Association

61% of members (36% of non-members) answering this question had donated to the MEA in the last 12 months, in addition to paying their subscription. We received 58 comments from those who had not felt able to donate, and these explained – in the majority of cases – that it was simply a case of not being able to afford additional support. Others tried to spread their money around especially to the other research charities in the UK, and some suggested ways – including some fairly ambitious ways – in which we might better attract more donations from outside of the community.

Donations to other ME/CFS national charities

25% of MEA members (43% of non-MEA members) answering this question had donated to charities other than the MEA in the last 12 months. We received 63 comments in total explaining why you might (also) have chosen to donate elsewhere and your reasons varied. Some believed that it was good to spread things around the sector, others chose charities that focused solely on research, others felt a certain aspect of another charity was worthy of your support or a specific research effort, and some mentioned they were attracted by individual efforts regardless of which charity the money was being raised for.

Membership of another ME/CFS national charity

39% of members answering this question indicated they were also members of other UK ME/CFS charities and we received 57 comments. Some indicated that by also belonging to another charity

they were benefiting from more information and getting another perspective on issues, others liked to spread their support around the sector, but some clearly felt that the MEA was not doing enough to support the severely ill and had joined a charity that they felt met this need or had joined this charity to show their solidarity around the issue. Others felt that by being a member of another charity it better enabled them to spread their own influence more widely, and some were clearly parents or young people seeking more specialised support.

Something MEA would do, or do better

39% of members (47% of non-members) answering this question indicated there was something they wished the MEA would do, or would do better. We received 103 positive comments and ideas, some of them quite detailed and we will be looking at them all carefully over coming months. Some of your suggestions included:

- Being more proactive with fundraising initiatives and having fundraising ‘packs’ available to those who might need them
- Establishing and supporting local groups
- Featuring personal stories more often in ME Essential magazine to help others feel less isolated and alone
- Introduce more summaries of information – especially with regard to research – that can be more easily digested
- Getting more articles about the illness and the research into mainstream media
- Better Christmas cards with information about the illness on them
- Research – investigate the brain and inflammation, look at possible hereditary nature and those most affected
- Support and information for those who manage to stay in work or who are not always as severely affected
- A leaflet that describes helpful stretching and body movement for ME
- A greater presence offshore and overseas
- More regular updates to the ‘Purple Book’ ME/CFS Key Clinical Issues
- A bigger and better quality ME Essential magazine with an e-version for those that want it

Membership

Asked how likely it was that you would renew your subscription, an overwhelming 95% of members indicated they would do so (86% indicating it was ‘very likely’), and 71% of non-members indicated that if they were able to afford it they were also likely to join The ME Association.

Recommending the MEA

We asked how likely it was that you would recommend The ME Association to someone you knew and a massive 95% of members indicated they would (71% indicating it was 'very likely').

A similar question was asked of non-members, based on their own knowledge and experience of the MEA, and 67% of those who chose to answer the question indicated it was likely they would recommend membership to someone they knew.

Describing the MEA

We provided a selection of over 20 words from which respondents could select the ones that they felt best described the MEA. They were able to choose as many words as they liked and could also include their own in the comments section. The top 10 words chosen to describe the MEA were:

Members	Non-Members
1. Helpful (83%)	1. Helpful (59%)
2. Credible (77%)	2. Supportive (49%)
3. Supportive (76%)	3. Credible (49%)
4. Honest (70%)	4. Communicative (44%)
5. Communicative (70%)	5. Respected (40%)
6. Expert (64%)	6. Honest (37%)
7. Respected (63%)	7. Expert (37%)
8. Understanding (62%)	8. Welcoming (35%)
9. Realistic (60%)	9. Understanding (35%)
10. Welcoming (57%)	10. Visible (24%)

"I feel that the ME Association bats above its weight and would love it to have more funding to enable it to do even more. I think that this sort of help would save wasted lives and government money."

"Short Staffed!"

"Instructive."

"Solid."

"Caring."

"Persistent!"

"Empowering."

"In all seriousness – at times – life-saving."

Conclusion

We were very pleased to read what you thought about our charity. Thank you to everyone who took part in the surveys. Your praise, suggestions and constructive criticism will help us plan the next few years.

There are several initiatives that we are currently working on which we hope will help address some of the issues that have been raised and they include:

- Improving the support for Dr Shepherd
- An Illness Management Guide
- An ongoing review of ME Essential magazine
- A new and improved research section for the MEA website
- Better representation and inclusion of those severely affected
- Consideration of a member-only forum
- Improving support for fundraisers
- Improving support for local groups
- Better communication of our message and activities

By acting on what you tell us, we can make The ME Association more effective in its role in informing, supporting and funding research into ME.