

MEMBERS SURVEY: Your Views and Your Experiences

Introduction

In March 2003 a randomly selected sample of 1,100 Action for M.E. members were asked to complete a questionnaire. 550 people received a 'your views' questionnaire and 550 received a 'your experiences' questionnaire.

'Your views' - 283 responses (51%)

'Your experiences' - 354 responses (64%)

The design and analysis of the survey was led by Lucy Campbell, Information and Research Nurse, and was supported by all the other members of the Wells based Information and Membership Teams. The thanks of AfME's Council have been placed on record for this work.

Caution

Whilst the results have already been used extensively to inform and influence policy, in referring to this data it must be stated that as with all membership organisations, the membership are not representative of the overall constituency. Nor does any survey match the standards of formally conducted research trials.

Where commentary is made on the data, this is shown in italics.

Summary

Who are our members?

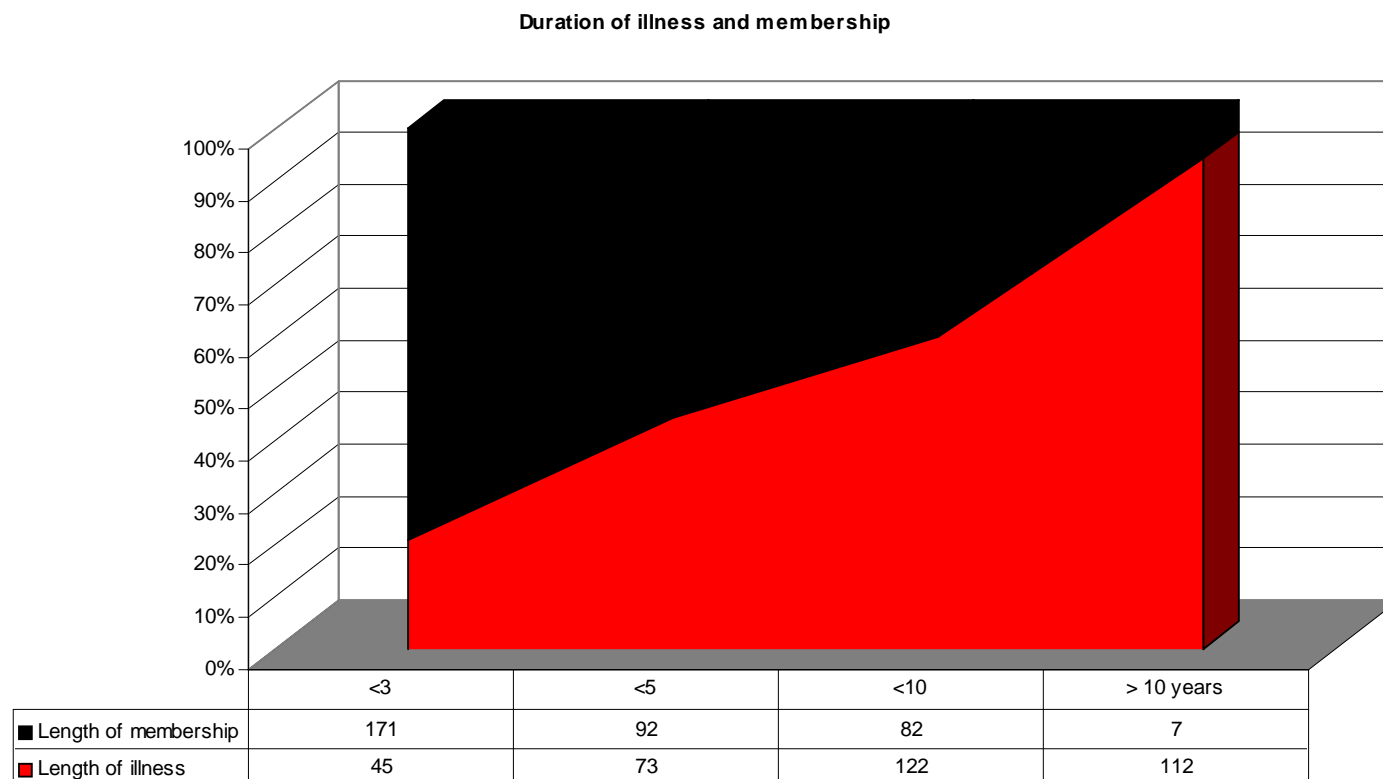
The survey would indicate that most are female (82%) and the majority are currently aged between 35 and 65 years (72%).

They are predominantly white and British (96.5%).

- *It is a concern that people from minority groups have been under-diagnosed. See AfME's 2000 Report on the experiences of people from black and ethnic minorities.*

Half have been ill for more than 10 years.

But most have been members for much shorter time, indicating a long time lag from first becoming ill to joining as a member.



There was no pattern for how people had heard of us, and very disappointing was the poor signposting from health professionals.

How did you hear of AfME?

- 38% - don't know / can't remember
- 22% - media
- 16% - friend or family
- 6% - healthcare professional
- 1% - internet

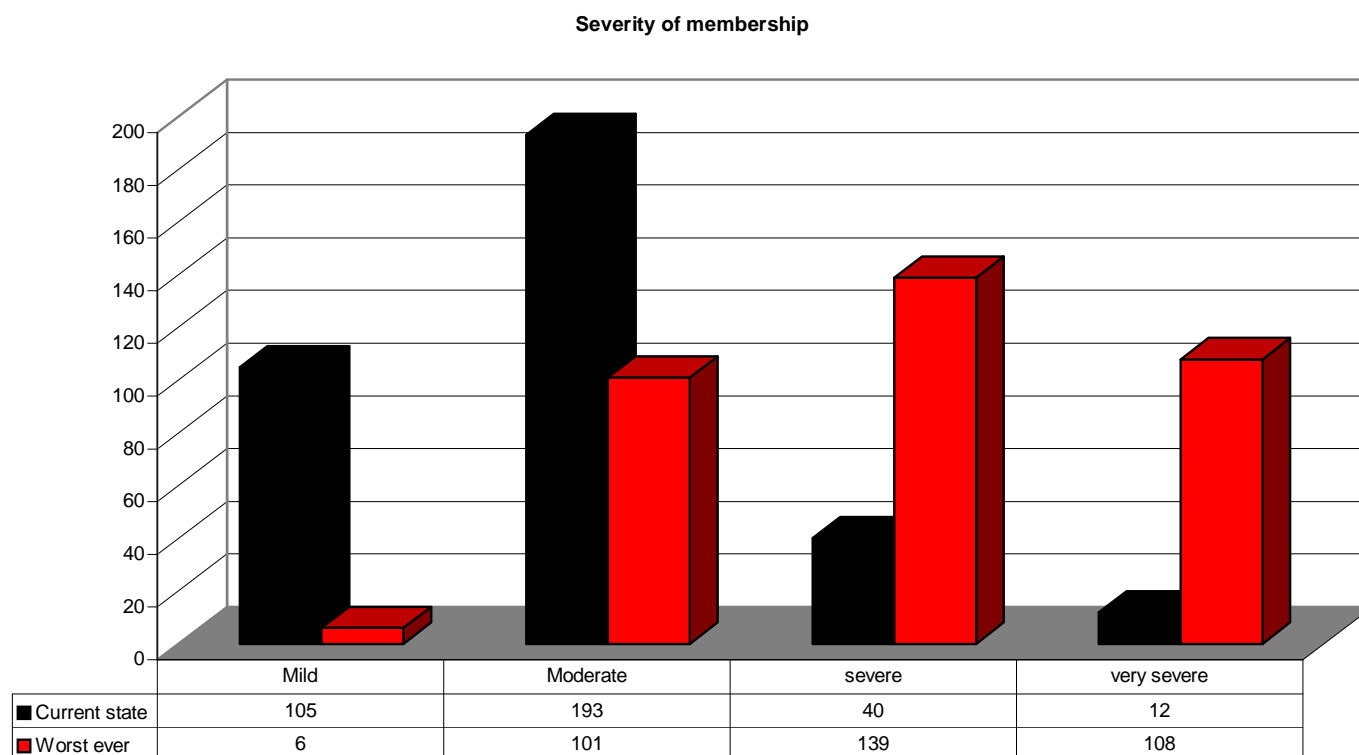
Two-thirds stated that their main reason for joining was to find out about the illness and how to manage it.

Half are not members of any other M.E. organisations.

Just over a quarter belong to a local support group.

Just over half (54%) described themselves as currently moderately affected. When asked to describe their worst ever level of disability 71% described it as severe or very severe.

- *i.e. many (but not all) people do improve, including those once very severely affected. This confounds views expressed by some that the approaches found beneficial by patient organisations help people to “live with the illness” rather than recover.*

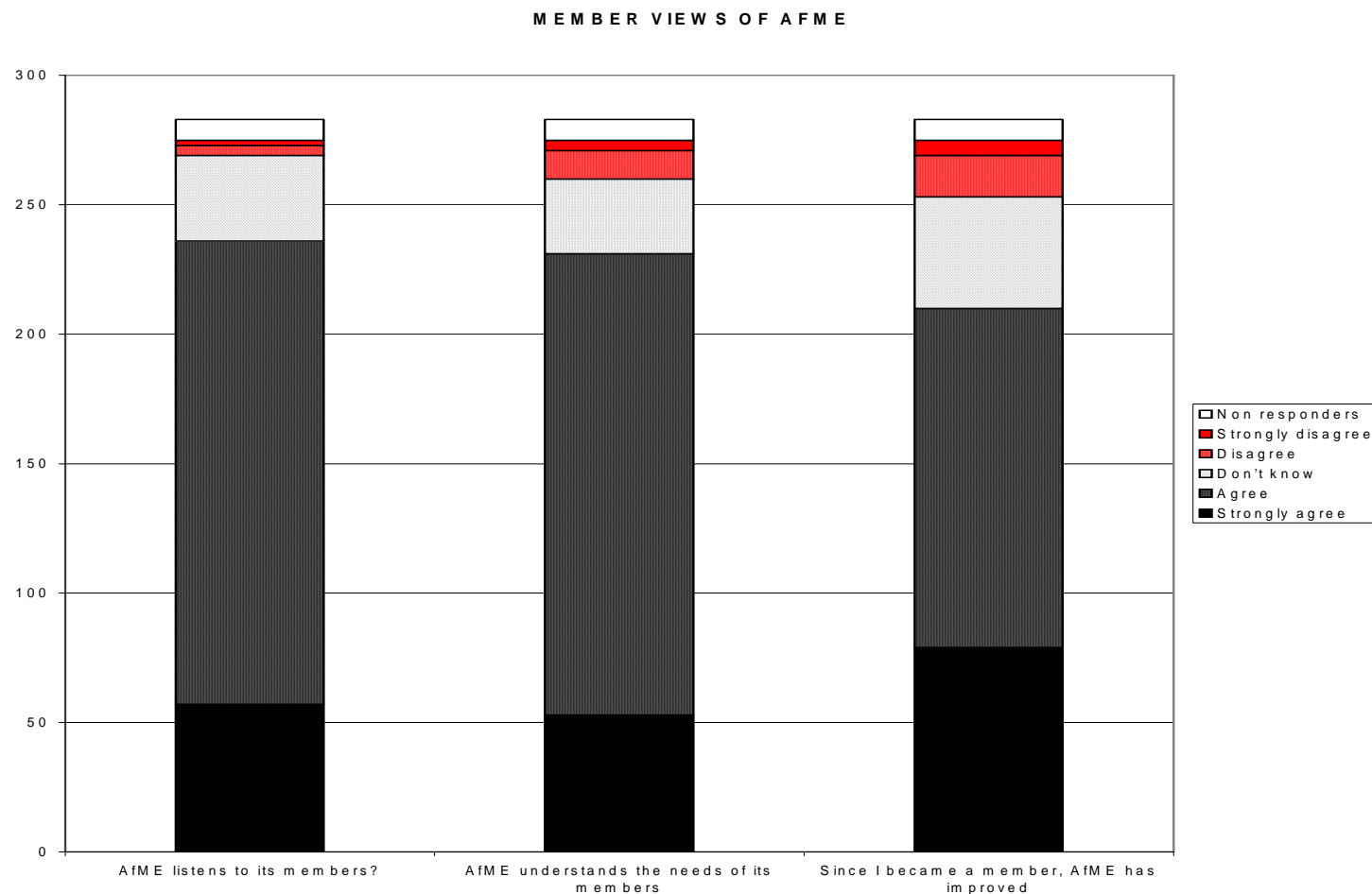


Results from 'Your views' questionnaire

We gave respondents a series of statements to look at and decide whether they agree or disagree with them:

- Their views of the charity:**

83% believe that the organisation listens to them and 81% believe we understand them. 2% think we don't listen and 6% that we don't understand.



74% think we have improved since they joined, with 8% disagreeing and 15% 'don't know'.

When asked whether the organisation had a positive approach to the illness, 93% agree.

We asked whether the information we produced was too mainstream or centre ground. 68% disagree or strongly disagree. 16% don't know.

- **Members Magazine - InterAction:**

85% agree that InterAction gives them the information they need. Only 9% think it is too depressing.

- **AfME policy regarding the Chief Medical Officer's report and views on its impact:**

82% think that AfME was right in supporting the CMO report. Only 3% disagree.

When we asked whether they thought attitudes had changed since its publication, 34% think they have changed for the better.

- *14 months had elapsed since the publication of the report and completion of the survey so it could be interpreted as having made a significant difference to a third of the membership.*

However, 35% believe that attitudes are the same; 25% are not sure. Only 1% think that attitudes have changed for the worse.

- **Campaigning:**

88% of those who responded agree that the organisation campaigns on their behalf to the media, as do 93% when asked if the organisation campaigns to government and the NHS on their behalf.

There is slightly less agreement (79%) regarding AfME's role in campaigning to professionals and 16% don't know. When asked later in the survey about their priorities, 90% think we should give more information to professionals e.g. GPs. As many as 55% strongly agree, a much higher result than for any other statement.

Around two-thirds agree that we should do more campaigning for the less severely ill and young people. Slightly more (three-quarters) think that we should focus more campaigning on the severely affected.

- *This may indicate that all groups are seen as important to members but that the severely affected are considered to need a higher profile.*

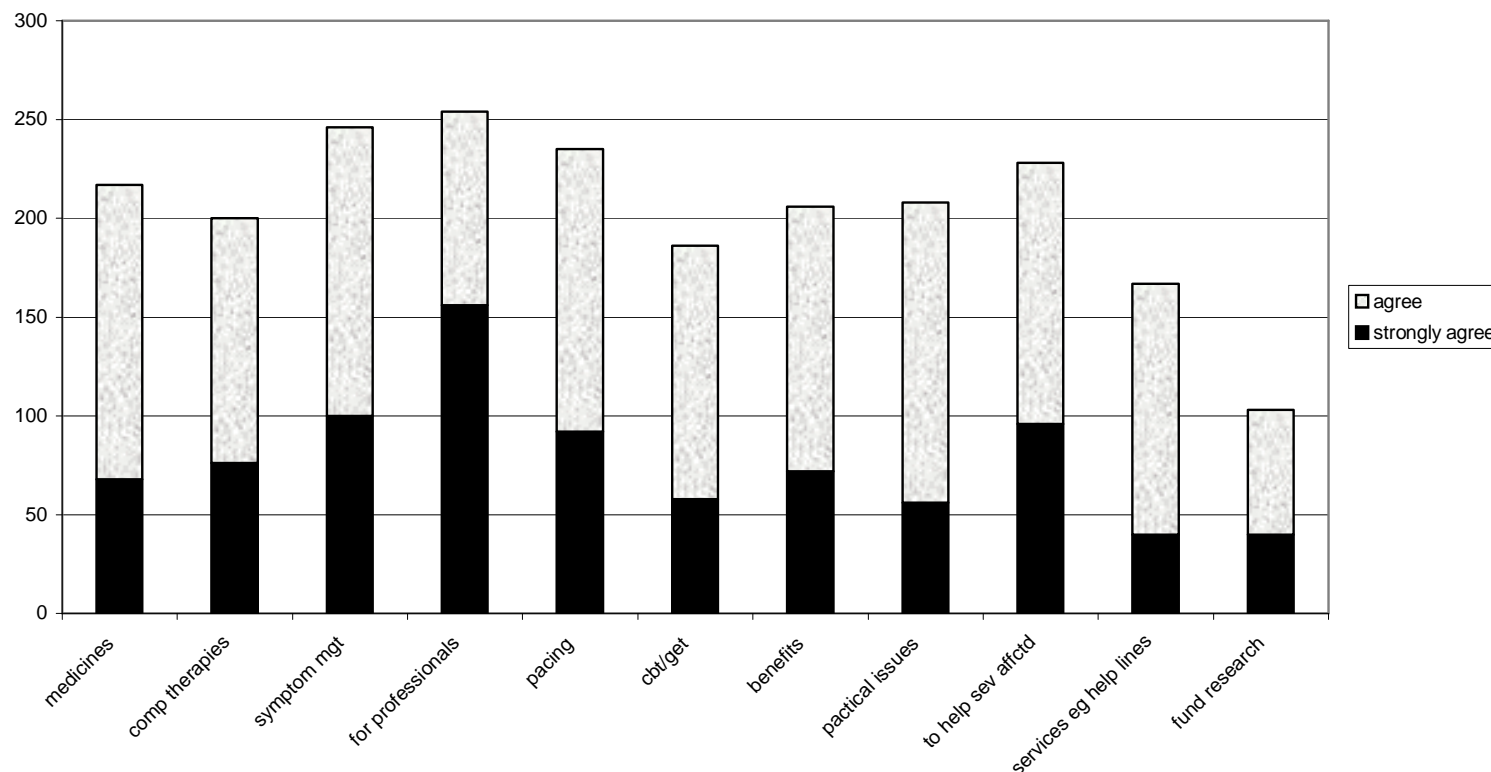
- **Information:**

Over 70% want more information on medicines, complementary therapies, symptoms and their management, welfare benefits and practical issues such as employment and travel.

84% want more information on pacing. We know from other surveys that pacing is considered helpful by the majority of our members and it is significant to note that such a high percentage want more information on *how* to pace.

AfME is on occasions criticised for providing information on Graded Exercise (GET) and CBT. As many as two-thirds feel that more information should be provided. However those who disagree totals 23%, a higher result than for other statements, underlining the controversy.

What Members Want



- **Services:**

Given that most people join to get information on the illness and its management, over half (59%) wanted more services such as help-lines, but this was a lower proportion than those who wanted information or more campaigning. 19% said they did not want more services.

- **Research:**

99% want more research into M.E., with 88% strongly agreeing – the highest response to any statement.

Opinion was evenly divided on AfME's role in raising funds to pay for research, with 36% agreeing that we should, but 39% disagreeing.

Results from 'Your experiences' questionnaire

- **Relationship with their GP:**

Just over a quarter of respondents see their GP about their M.E. every 1-3 months. A significant number (24%) see their GP less than once a year.

Just over half think the relationship is supportive and constructive and that their GP is a good listener and shows an interest in M.E. However, a substantial minority are either uncertain or disagree.

As many as 58% believe that their GP considers M.E. to be a physical illness with only 10% disagreeing.

Disappointingly few consider their GP is willing to try new approaches (40%); has ideas for symptom control (31%); or is interested to find out more (28%). This may support the findings in the 'your views' questionnaire where 90% want more information to be given to professionals.

- **Specialist care:**

Half have seen an NHS specialist about their M.E. in the last 3 years. Two-thirds found them to offer a professional approach and felt they were listened. However one-third did not find that the appointment was useful or that it made a positive difference to their health.

Neurologists were the most common specialist seen. Only 12 out of 171 had seen psychiatrists.

- *This is of interest given the perception that psychiatrists are dominant in the field.*

- **Inpatient care:**

63 of the 354 respondents had been admitted to hospital overnight or longer because of their M.E. 26 of the 63 had been admitted for 7 days or longer. Generally the experience was neutral, negative or considered to make no positive difference to their situation.

- **Private doctors:**

In view of the lack of NHS support it may be of little surprise that 60% of members saw a doctor privately, and the average spent was £400.

- **What helps:**

We asked respondents to decide how helpful different approaches had been:

Medication prescribed by their doctor was considered helpful by only 55% of those who had medication prescribed.

Of those who tried making changes to their diet, 59% were helped although 25% were uncertain and 16% reported feeling worse.

Rest, including bed rest, helped a significant 90% although this was asked in very general terms and we did not ask them to differentiate between rest in the very early stages of their illness compared with rest in the more chronic stages.

- **Prescribing of antidepressants:**

84% had been prescribed antidepressants. We asked what explanation was given by the prescribing doctor for the use of these drugs. 64% were advised that the drugs could help with M.E. symptoms. 20% were advised that they would help with mood problems. 65% were happy with the explanation they received.

- **Complementary therapies:**

We asked how much approximately they had spent on complementary therapies in the last year. 38% had not spent any money; 25% had spent over £500 in the last year. When we asked whether complementary therapies had helped their symptoms 44% agreed that they had. The most popular were acupuncture, reflexology, homeopathy and massage.

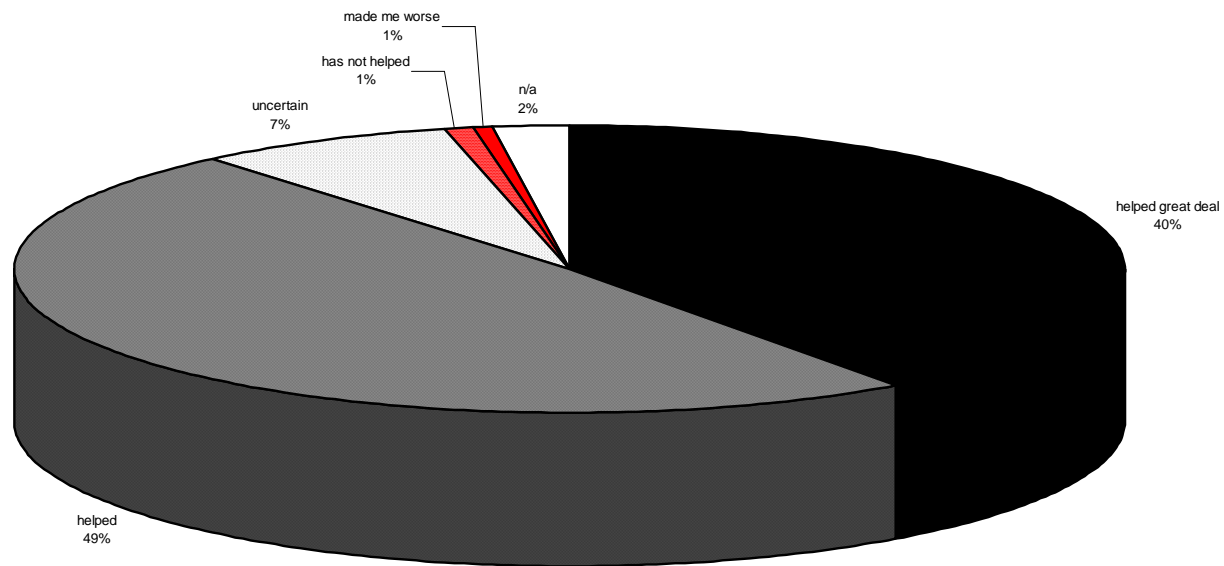
- **Nutritional supplements:**

When asked how much they had spent on nutritional supplements in the last year, only 28% replied nothing. A significant 73% had spent over £100 in the last year. When we asked whether nutritional supplements helped, 51% said yes they had helped but another 36% were uncertain of their benefit.

- **Pacing:**

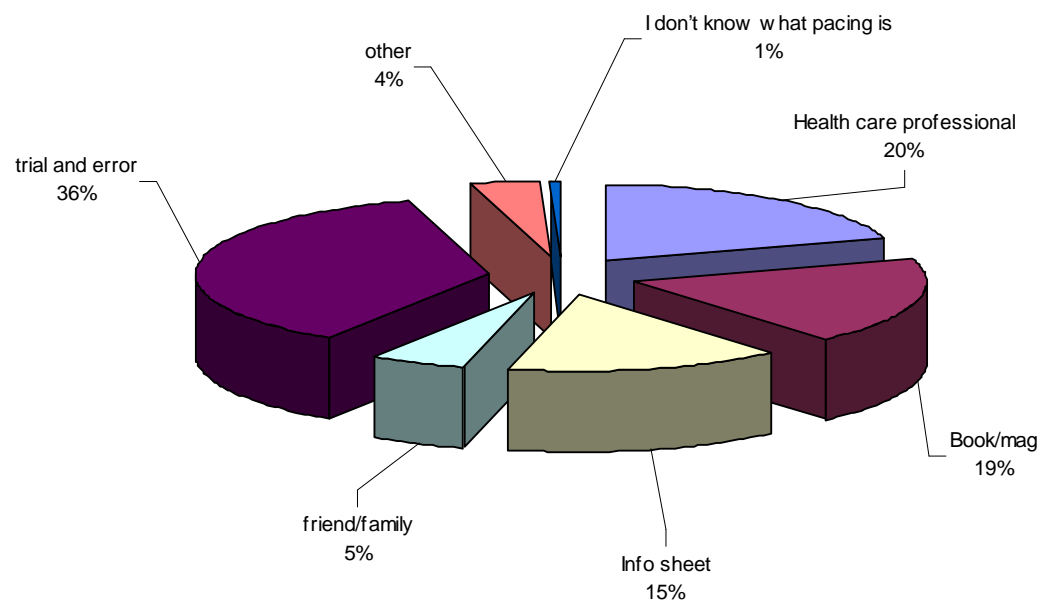
Pacing had helped a very significant **90%** which echoes findings in previous surveys.

Pacing Outcomes



When we asked them how they learned to pace the most common way was by trial and error and respondents usually used a variety of ways to learn the technique.

HOW PEOPLE LEARN PACING



A clue to why it is successful is that 87% understand what causes a relapse – thus enabling people to manage their activities, be empowered and take control of their illness.

ACTION for M.E.

- *We are now analysing the detailed descriptions given, and our objective is to define and better inform others about pacing, ensuring better information is given to people with M.E. and it is included in NHS practice [Major projects for 2004.] Additionally the detailed descriptions have been directly used to construct the pacing arm of the research study, PACE.*

- **Access and overall outcomes to graded exercise therapy and cognitive behavioural therapy:**

Despite the controversy, graded exercise therapy had been tried in the last 3 years by only 16% of those surveyed (and less than half of all those surveyed)

As with previous surveys around half found these helped them and half harmed them.

However as these results are so different from research results from research studies and because rehabilitation approaches remain so controversial (and NOT because we support them) we looked in more depth, particularly as those with recent experiences ie in the last 3 years.....with interesting results.

- **Outcome by severity at worst**

We looked at those who had had positive, neutral and negative outcomes and compared these with their stated severity when worst (noting 70% had been very severely affected .v. 15% currently so)

50% of those with negative outcomes had been v severe
38% of those with neutral outcomes had been v severe
19% of those with neutral outcomes had been v severe

This may have significant implications for national policy, but needs further study.

- **Graded Exercise Therapy (GET):**

GET is one of the most controversial of the rehabilitative approaches, and is usually supervised by physiotherapists. As was reported by the CMO's Working Group, practice varies enormously.

When those who had had GET in the last 3 years were examined in more depth, a high proportion had never in fact had GET as reported in research studies e.g.

11 Had NO professional input (*had they therefore paced themselves ?*) – mostly with positive outcomes
6 Were supervised by occupational therapists – **all with negative outcomes**
3 Had been sent to the gym- **all negative outcomes!**

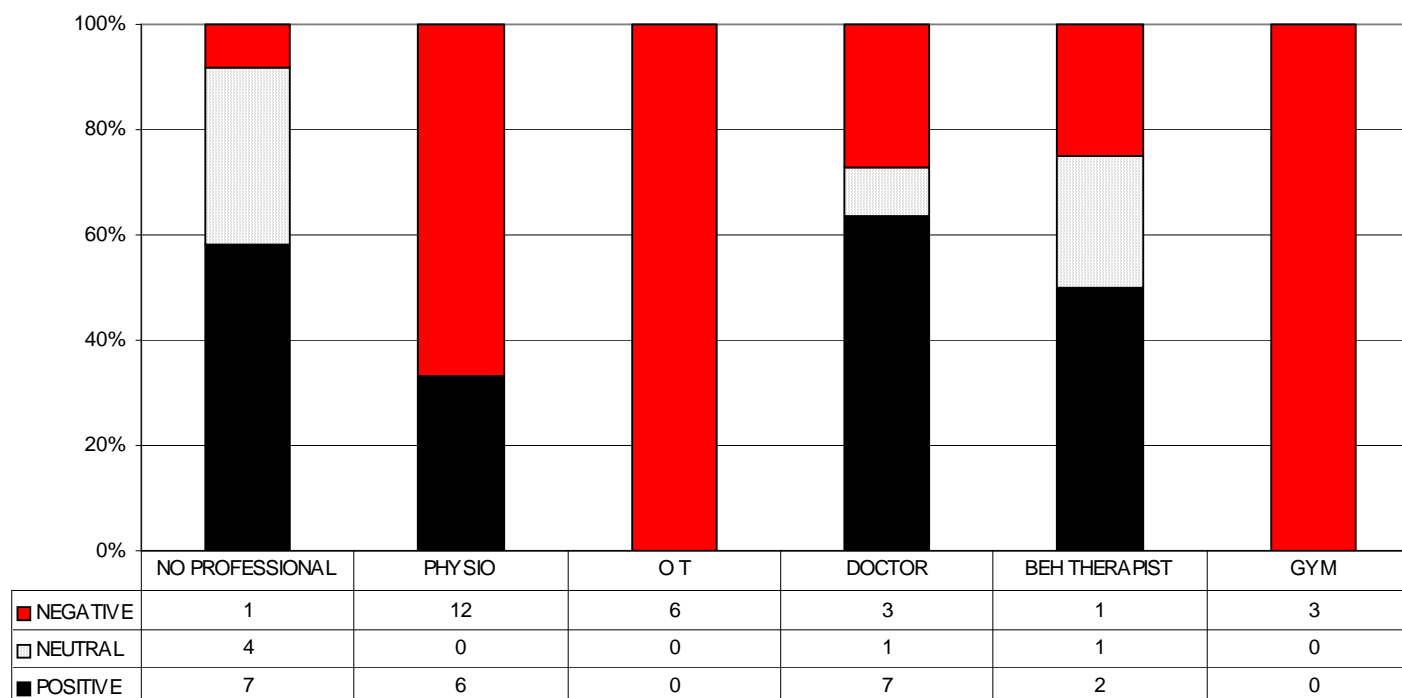
ACTION for M.E.

- *This appears to show that outside the major M.E. centres, who does it and to what standard is a lottery. Suggesting that the issue may not be the value of GET, but what type and the quality of the therapist. This would certainly support the evidence given to the CMO Report, and if true could explain why harm is not found through research trials (conducted in the best centres) but is found through surveys of peoples experiences – few having had access to the best centres.*

This is further demonstrated by the positive and negative comments appended at the end, suggesting major problems with setting baselines from which to begin and setting over-demanding targets – issues well understood in the leading centres.

AfME is taking this up with the professions and through the new NHS services to be established.

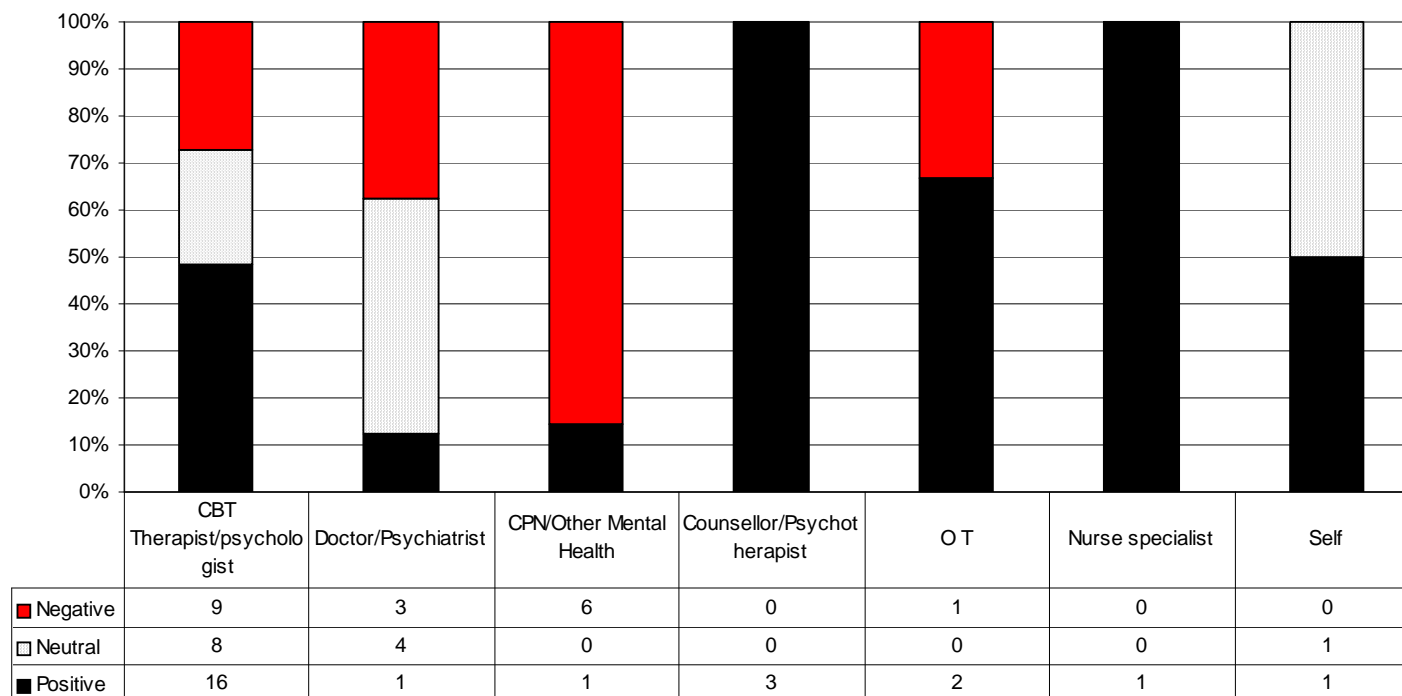
GET BY PRACTITIONER



- Cognitive Behavioural Therapy (CBT):**

As with GET, a variety of practitioners are providing CBT with mixed results e.g. Community Psychiatric Nurses = all poor outcomes. However the therapists who were involved are more difficult to “group” than with GET.

CBT BY PRACTITIONER



When examining positive and negative comments, issues repeatedly crop up about language and relationships – again indicating the problem may not be CBT, but poorly practised CBT. See appendix for examples.

- Employment:**

ACTION for M.E.

We asked those respondents who had lost their job while ill with M.E. to specify whether this was a voluntary decision or forced upon them. Of those individuals (195) who were in work and who had lost their job because of their M.E. (55% of those asked), 31 were dismissed and another 31 were forced to resign. The most helpful strategies cited by those that had managed to stay in work were reduced or flexible hours and reducing or stopping all social activities.

Chris Clark
Action for M.E.
4.2.04 (revised)

APPENDIX – EXAMPLES OF WHAT PEOPLE SAID ABOUT GRADED EXERCISE (GET) AND COGNITIVE BEHAVIOURAL THERAPY (CBT)

POSITIVE - GET

- ‘This was so gradual/measured and monitored that it did no harm and did not worsen the M.E.’
- ‘The physio was v understanding, listened & didn’t push me too far’.
- ‘It helped me find my limits and then extend these at a pace which suited me, as a result I am now more active. I was in control of increasing the exercise, the amount or duration was not prescribed. It was part of the programme including pacing’.
- ‘This was so gradual/measured and monitored that it did no harm and did not worsen the M.E.’
- ‘The physio was v understanding, listened & didn’t push me too far’.
- ‘It helped me find my limits and then extend these at a pace which suited me, as a result I am now more active. I was in control of increasing the exercise, the amount or duration was not prescribed. It was part of the programme including pacing’.

NEGATIVE GET

- ‘She began me at too high a level and I ended up in bed for days. I found that to exercise I had to stop EVERY other activity in my life’.
- ‘Too ill to get a base line from which to move’.
- ‘Far too aggressive when presented with a severely affected patient’.
- ‘Too intensive for me.....’.
- ‘Got worse am trying again..... feel started/aimed too high’.
- ‘.....went too fast & left me ill again’.
- ‘.....very bad idea. Pushed me too hard too fast, I had a severe relapse and would NOT recommend it’.
- ‘Exercise offered by gym - equipment too strenuous for my needs and resulted in viral flare up and exhaustion’
- ‘Became severely affected as a result of this’.
(Rheumatologist told me to exercise at the gym).

POSITIVE - CBT

- The therapist didn't offer a cure but aimed to help me cope with M.E. We worked out an activity/rest schedule which worked. I would have liked "top up" sessions but none were available
- Gave me confidence to return to work but I really used it to gain time for my own pacing activity and helped me stay gainfully employed
- enabled me to be nicer to myself, allowing me to cope with the illness better, just doing what I can from day to day

NEGATIVE - CBT

- Therapist controlling and disapproving, don't think she believed me.....
- Found approach unsuitable to my needs at that time and resulted in loss of confidence in any recovery and worsening symptoms
- made to feel it was my fault that I was ill, made to push myself to do more even though harmful.....

Note:

308 descriptions of pacing were recorded and these are subject to separate analysis as part of a major project for 2004, which will lead to:

- *PACE trial informed by the actual voices of people with M.E.*
- *New AfME information materials*
- *Influencing the NHS to adopt pacing*
- *Preparation for a referral to NICE*