

Combined results – therapies most in favour appear first

Type of therapy	Number of replies	Greatly improved	Improved	No change	Slightly worse	Much worse
PACING	2137	11.6%	59.6%	24.1%	3.5%	1.2%
MEDITATION OR RELAXATION TECHNIQUES	1675	6.1%	47.6%	44.3%	1.6%	0.4%
ALLERGY TREATMENTS	686	9.5%	41.7%	45.2%	2.2%	1.4%
MASSAGE	1037	5.4%	43.9%	31.3%	12.7%	6.7%
OSTEOPATHY/ CHIROPRACTIC	774	9.8%	42.1%	33.3%	10.1%	5.7%
LIGHTNING PROCESS	101	25.7%	18.8%	34.7%	7.9%	12.9%
PERRIN TECHNIQUE	115	13.2%	37.4%	37.4%	6.7%	4.3%
CORTICOSTEROID EG. HYDROCORTISONE	323	10.6%	32.5%	35.3%	10.8%	10.8%
HYDROTHERAPY	275	4.0%	37.5%	32.0%	13.4%	13.1%
YOGA	812	4.2%	34.8%	32.9%	20.8%	7.3%
ADVICE (TO HELP ME TO COPE)	2147	3.3%	39.5%	50.9%	3.7%	2.6%
THYROXINE	414	8.7%	30.4%	50.0%	6.0%	4.9%
EICOSAPENTAENOIC ACID (EPA) OMEGA 3 OIL	1217	3.2%	33.1%	59.7%	2.9%	1.1%
MODAFINIL/PROVIGIL	81	14.8%	22.2%	33.3%	16.1%	13.6%
L CARNITINE	318	2.8%	28.0%	62.9%	3.8%	2.5%
VITAMINS AND SUPPLEMENTS	2370	3.7%	31.9%	61.9%	1.8%	0.7%
REVERSE THERAPY	107	8.4%	21.5%	45.8%	16.8%	7.5%
HOMOEOPATHY	1100	5.4%	24.4%	59.9%	7.1%	3.2%
OIL OF EVENING PRIMROSE (OEP) OMEGA 6 OIL	1231	2.6%	25.8%	66.3%	3.7%	1.6%
PHYSIOTHERAPY	862	3.5%	27.0%	36.7%	17.1%	15.7%
COUNSELLING (OTHER THAN CBT)	984	2.6%	26.8%	60.1%	6.1%	4.4%
COGNITIVE BEHAVIOUR THERAPY (CBT)	997	2.8%	23.1%	54.6%	11.6%	7.9%
INOSINE PRANOBEX/ IMUNOVIR	62	8.1%	17.7%	50.0%	16.1%	8.1%
NADH	358	3.3%	16.5%	63.4%	12.3%	4.5%
GRADED EXERCISE THERAPY	906	3.4%	18.7%	21.4%	23.4%	33.1%

THE MEA BIG SURVEY

All the results are in from the largest-ever survey of opinion of people with ME/CFS carried out last year by The ME Association.

They confirm that using that Graded Exercise and Cognitive Behaviour Therapy as front-line treatments for the illness – as recommended by the National Institute for Health and Clinical Excellence (NICE) – have very little support from sufferers.

In fact, a significant majority of those who had tried graded exercise – 56% – said it had harmed their

Survey Numbers

4,217

PEOPLE TOOK PART

3,494

TOOK PART ON-LINE

723

MEA MEMBERS COMPLETED THE PAPER QUESTIONNAIRE

56%

SAID GRADED EXERCISE MADE THEM FEEL WORSE

72%

FOUND PACING HELPFUL

4

FOUR MONTHS AND A BIT - THE TIME THE SURVEY WAS KEPT OPEN

SURVEY – MORE HEADLINE RESULTS AND OPINIONS

health rather than made them feel better.

The combined results from those taking part online and MEA members who completed the paper questionnaire were passed across to the legal team behind the High Court challenge to the NICE Guideline in February – in case they were useful to their case.

A total of 4,217 people took part in the survey when it was held open for a little over three months last year. The comments they provided – reams of them, too many

and too complex to report in detail here – will provide the backbone for a major report which The ME Association will be preparing on management practice of the illness.

We hope it will show how flexibility in the care and management of people with ME/CFS, and greater innovation, needs to be built into official, medical guidance in the future.

The results indicate those therapies and treatments which people with ME/CFS found most helpful. And those which, while attractive to

a small minority, do not appear to be beneficial to the greater number.

But, for those thinking about using fashionable and speculative therapies, like the Lightning Process (LP), we have to report that the survey shows the jury is still out on whether they really work for neurological ME. The numbers involved in the survey who had actually tried LP are really too small to draw any firm conclusions. In the meantime, we remain highly sceptical about their value for people with ME.

Taken from the online results

How do you rate your current standard of medical care?

		TOTAL
Excellent	5.7%	150
Good	19.2%	504
Average	25.3%	663
Poor	17.0%	446
Very poor	11.8%	310
Not receiving any	20.9%	548

Is your medical adviser well-informed about the diagnosis of ME/CFS?

Yes	26.2%	688
Partly	33.6%	880
No	40.2%	1053

Is your medical adviser sufficiently aware of the range of therapies available?

Yes	14.7%	386
Partly	31.7%	832
No	53.5%	1403

Symptoms experienced by online participants

	MAJOR	MINOR	TOTAL
Still feeling tired on waking up	2709	183	2892
Feeling generally ill for several days after minor exertion	2607	256	2863
General malaise that varies through the day	2399	380	2779
Poor concentration span and poor short term memory	2152	726	2878
Severe muscle weakness after minor exertion	2094	635	2729
Muscle pain	2063	739	2802
Inability to cope with temperature changes, or night sweats	1834	818	2652
Aching joints without swelling or redness	1816	828	2644
Increased sensitivity to light and/or sound	1554	1063	2617
Irritable bowel problems	1529	954	2483
Headaches of a type not previously experienced	1527	1070	2597
Problems remembering names of people and objects	1527	1110	2637
Dizziness or feeling faint on standing (postural hypotension)	1365	1221	2586
Sleeping in the day time rather than at night	1247	1162	2409
Problems with balance	1116	1404	2520
Recurrent sore throats and enlarged glands	1113	1430	2543
Alcohol intolerance	1079	1200	2279
Sensory changes eg. tingling or abnormal skin sensations	986	1384	2370
Twitching of muscles or eyelids	863	1568	2431
Difficulty in finding your way about	518	1538	2056
New allergies	869	1241	2110