



YOUR EXPERIENCE OF ME SERVICES



Survey report by
#MEAction UK

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APPENDIX 4

Appendix 4 - Multidisciplinary team 'other' responses

Preferred composition of multidisciplinary team

Out of the 1338 total number of responses, 189 people chose other, with 48 leaving no comment. Of the 141 that left comments, there were 46 mentions of wanting to see someone with knowledge of or who specialises in ME, with no specific opinion on what role they should be in.

"A specialist who is up-to-date with all current ideas and developments with regard to ME/CFS."

"I think this could be flexible, the important part is that the staff are knowledgeable, interested and want to be there."

There were 34 mentions of the specific sort of consultant people would like to see on the team, the most common being neurologist at 18 mentions. 16 responses mentioned a desire for access to alternative medicine, and 14 mentioned having someone with lived experience of ME on the team.

There were several suggestions of others who should be on the multidisciplinary team that had less than 10 mentions.

- An advocate/social worker or help from social services (9).
- Help from allied health professionals such as occupational therapists or physiotherapists if the advice/guidelines were different (8)
- Other suggestions of team members that were too few to fit into any of the other codes (7)
- People who did not want help/didn't trust the medical profession (6)
- Mentions of wanting a multidisciplinary team (6)
- Pain management (5)
- Nutritionist (5)
- Counsellor (3)

All 'other' comments.

1	<i>Functional medicine practitioner</i>
2	<i>Nutritionist</i>
3	<i>Pots specialist</i>
4	<i>Neurologist, immunologist, endocrinologist, cardiologist</i>
5	<i>counsellor</i>

6	<i>It's important to have specialists (consultants, specialist nurses, OTs and physios) who will do home visits. A specialist physiotherapist who UNDERSTANDS ME and will NOT push the patient. Not to give advice on increasing activity levels but someone who can help those who are bedbound with flexibility exercises and to keep range of motion and so stiffness and pain doesn't set in. But again must re iterate please no physios telling us to increase activity level or GET or an increasing activity type of pacing. That's not helpful at all and caused harm to me.</i>
7	<i>Neurologist and Cardiologist</i>
8	<i>'Consultant' begs the question, 'Consultant what?' We need a multidisciplinary team of consultants.</i>
9	<i>At the moment, I fear that attempts to provide care for people with ME/CFS are likely to be counter-productive. A big improvement from what we have now would be to just be honest about how little we have to offer and then leave patients alone to live their own lives. I don't think that people with ME/CFS should be advised to do more, less, or the same level of activity. We do not have good evidence to underpin any such advice (I wish I could have made that clear in response to an earlier question which required me to give an answer I disagreed with), so why pay medical professionals to act as guides to patients' activity levels?.</i>
10	<i>Have ticked physio but not just to promote GET. Rather to address physical consequences eg poor posture, back & joint pain.</i>
11	<i>Specialists trained in ME</i>
12	<i>Someone who was honest when they didn't know and who treated patients with dignity and respect.</i>
13	<i>It needs treatment by someone who is aware or has had m.e cfs</i>
14	<i>Trained professional</i>
15	<i>Someone who understood ME, who was humble enough to be honest when they didn't know the answer or when there is no treatment, and someone who treats all their patients with respect</i>
16	<i>Someone who was uptodate on what science was really saying about ME, and who understood why the weird coercive form of CBT they do is so damaging to people's mental health, and GET is damaging to patients physical health. And someone who was kind.</i>
17	<i>Someone with a science background who understands that the syndrome requires hard work to get to the bottom of</i>
18	<i>Nutritionalist</i>
19	<i>Immunologist and a cardiologist and a neurologist</i>
20	<i>Scientists working on the front line</i>

21	<i>Pain consultant</i>
22	<i>Rheumatologist</i>
23	<i>Literally anyone who knows the condition and can actually provide help, no matter what their title is. I would feel least comfortable with a Gp as most experiences I have they have questioned if the condition even exists</i>
24	<i>Osteopath who has been trained in the Perrin Technique</i>
25	<i>People with modern specialist ME knowledge</i>
26	<i>ME specialist</i>
27	<i>Exercise physiologist IF know about the disease, CPET etc</i>
28	<i>Non biased Neurologist</i>
29	<i>Kinesiologist, holistic therapist, neurologist, dr with experience of microbiology, counsellor</i>
30	<i>some one trained in biomedical ME</i>
31	<i>Social worker</i>
32	<i>Someone with specialised knowledge of the most recent research and most supportive treatments</i>
33	<i>Named person to coordinate social care (huge battle), benefits, equipment as if you dont fight you dont get help but that fight further damages health and causes pem</i>
34	<i>Some actual M.E professor's</i>
35	<i>a "patient champion" who would do or facilitate everything to make things happen - up to date with current medical knowledge of ME, fasttracking paperwork/benefits evidence, etc., providing concise info (e.g. pro's/con's) on proposed treatment/meds, etc.</i>
36	<i>Pain Management</i>
37	<i>there is no such disease entity as me/cfs</i>
38	<i>No one from the medical profession!!</i>
39	<i>patient representative who has been diagnose under a strict protocol as having me/cfs your several years.</i>
40	<i>Consultant Physician with knowledge of POTS/Dysautonomia, MCAS, EDS, hypermobility, Crohn's & coeliac disease</i>
41	<i>Functional medicine doctor, neurologist conversant with WHO definitions of ME</i>
42	<i>Someone who has the condition and knows what they are talking about</i>

43	<i>Neurologist, immune therapy specialist</i>
44	<i>People who actually understand that M.E is not psychosomatic and have read the research that indicates physiological pathology rather than the fabricated concept of 'nothing there'. Everything that can be measured by the NHS is seen as unrelated to my M.E and the things which can be measured privately, saliva cortisol, mitochondria function, carcinogenic mould in urine, is seen as 'unscientific' regardless of the methodology or the fact many research papers use saliva cortisol testing, for example, in non m.e related experiments.</i>
45	<i>ME specialists who could help with diagnosis, and help people with managing their symptoms. I feel very strongly that pacing is key and a lot more support and guidance needs to be given to people on this topic.</i>
46	<i>Nutritional Therapist</i>
47	<i>Holistic methods</i>
48	<i>Somebody who can teach patients how to adapt home life, cooking, etc in a practical way to reduce exertion and better manage within their limitations as going beyond them constantly, just to survive, causes more harm and deterioration. We need specially trained people to give correct and appropriate advice from the onset for best chance of improvement.</i>
49	<i>Homeopathic Hospital</i>
50	<i>Osteo or hands on physio who actually treats rather than sets exercises and goals</i>
51	<i>Cfs specialist.</i>
52	<i>mindfulness teacher</i>
53	<i>Osteopath</i>
54	<i>The Me Association and Action for ME should have serious input.</i>
55	<i>immunologist, endocrinologist</i>
56	<i>someone who is not stuck in the 1980's and who is willing to look at individual symptoms and treat them accordingly</i>
57	<i>Massage therapist (maybe under physiotherapist) to relax muscles.</i>
58	<i>Neurologist</i>
59	<i>Alternative holistic based healing eg: acumpuncture, essential when the root cause of an illness is NOT known, this is the most vital relief, from disciplines, often non-Western biased, treating the WHOLE person.</i>
60	<i>Counsellor for support</i>
61	<i>ANYBODY who TRULY knows the appalling treatment to which we have been subjected, and can protect us from further abuse.</i>

62	<i>Infectious disease specialist</i>
63	<i>Multi disciplinary team</i>
64	<i>A retrovirologist or a virologist.</i>
65	<i>A specialist who is up-to-date with all current ideas and developments with regard to ME/CFS.</i>
66	<i>virologist</i>
67	<i>Advocates</i>
68	<i>This is pretty pointless since no-one has any answers yet, so no-one can help</i>
69	<i>ME/CFS trained personnel</i>
70	<i>Someone with expert knowledge of biomedical neurological ME, current, fully up to date with the latest research and NOT a biopsychosocial, CFS, CBT, GET, psychologist and PACE advocate</i>
71	<i>A medical professional, with UP TO DATE knowledge of the lived reality of ME, and current thinking, and research outcomes, about cause and effect, re symptoms and treatment options. Not a medical professional with a blinkered approach to the biological symptoms, and lived reality of ME.</i>
72	<i>Someone trained to give treatment based on the Perrin Technique.</i>
73	<i>The Psychologist to help with depression that one often gets when one is severely exhausted every day for years and been too ill to work or have a family etc. An outreach team or telephone/video team. A specialist nurse, a Specialist Social worker, Occupational Therapist also helpful.</i>
74	<i>Local support group</i>
75	<i>Chiropractor, neurologist, endocrinologist</i>
76	<i>I would tick GP but sincerely believe they would be more harmful to the patient than helpful.</i>
77	<i>Pain management nurse/doctor</i>
78	<i>Physio for ME</i>
79	<i>Someone who has first hand experience of the conditions</i>
80	<i>Patient or representative</i>
81	<i>Patient or representative.</i>
82	<i>Competent consultant, occ therapist and dietician</i>
83	<i>Doctors only</i>

84	<i>Neurologist / Doctor who can monitor sleep disturbance, immune system fluctuations and PEM with stress tests, as well as assess for POTS etc.</i>
85	<i>Why only 3 choices? We need specialist, trained staff for all aspects of treatment - physical, psychological, diet etc.</i>
86	<i>Someone who actually understands ME who has an open mind and who LISTENS to the patient instead of making them feel it is all our own fault</i>
87	<i>A person with experience of living with cfs</i>
88	<i>Social Services</i>
89	<i>Neurologist</i>
90	<i>Neurologist, ME specialist</i>
91	<i>The consultant and their team must be specialists. There is a need for a speciality for ME in its own right.</i>
92	<i>Specialist medical doctor, could be Specialist GP or consultant</i>
93	<i>Consultant without PACE bias</i>
94	<i>A person with ME who have found ways of working with ME</i>
95	<i>Someone who understands M.E. is up to date with medical research and evidence of M.E. NOT a physiotherapist or psychologist, they are not helpful.</i>
96	<i>Someone who will test for deficiencies, blood, endocrinology, toxins etc.</i>
97	<i>Someone who can order and understand the bodys nutrients, blood, hormon levels should be measured. Toxins, metals, organ function, Gut flora tested.</i>
98	<i>A consultant or doctor who knows about ME who is NOT from a psych background.</i>
99	<i>Neuro, clinician & a GP all TRAINED & knowledgable with upto to date ME knowledge, advice & research</i>
100	<i>Neurologist/Immunologist</i>
101	<i>Specialists/consultants in pituitary illnesses</i>
102	<i>All should be highly educated on ME or not involved. OT would be great too.</i>
103	<i>Any or none of the above if they are not knowledgeable about ME & not aware of the latest scientific research. As you become more intolerant the more severe your condition is a dietician would also be hood as would a psychologist not for CBT but for emotional support with a chonic illness</i>
104	<i>None of the above. Theyve all proved useless imho.</i>
105	<i>Pain expert</i>

106	<i>endocrinologist and / or immunologist</i>
107	<i>It should be multi-disciplinary with an overarching senior lead who is PASSIONATE and motivated in research and an open-minded attitude</i>
108	<i>Alternative therapies</i>
109	<i>Immunologist. Anyone with up to date knowledge of contemporary research</i>
110	<i>Advocate.</i>
111	<i>All of the above and other consultants/specialists where certain complex cases are concerned</i>
112	<i>I think this could be flexible, the important part is that the staff are knowledgeable, interested and want to be there.</i>
113	<i>Anyone who actually spends time researching this illness and not just 'going by the NHS book'</i>
114	<i>Functional medicine practitioner</i>
115	<i>Anyone who is up to date with current research from OMF etc</i>
116	<i>Local supportive professional</i>
117	<i>sufferer</i>
118	<i>Neurologist</i>
119	<i>Person diagnosed with ME</i>
120	<i>Pain relief specialist. Practical support. Employment Law specialist</i>
121	<i>Immunologist</i>
122	<i>Someone with a full understanding of the disease.</i>
123	<i>Someone with the illness.</i>
124	<i>Continence nurse</i>
125	<i>Access to a mixed specialism team eg. Neurology, endocrinology, cardio, rheumatology etc</i>
126	<i>Nutritionist. Infectious diseases specialist to take care of viral reactivations, allergist.</i>
127	<i>Osteopath/soft tissue/trigger point therapist.</i>
128	<i>Neuro physiotherapist</i>
129	<i>OT and/or physio to support energy conservation rather than focus on increase</i>

130	<i>ME Association Rep as they have consistently been the only source of accurate advice of benefit to me, eg pacing, not pushing on through ME flare up as feel guilty, lazy, etc</i>
131	<i>No psychologists who tend to palm CFS of as depression when you are in agony, so it blatantly is not. No consultants, they lacked medical knowledge and seemed to have just done a weekend course</i>
132	<i>Cardiologist for POTs and orthostatic issues, neurologist, bladder expert - we need all the above to help the various symptoms</i>
133	<i>neurologist</i>
134	<i>Anyone who has specific knowledge of ME</i>
135	<i>Doctors specialising in pathological illness rare disease, chemistry of cells and cellular energy delivery and consultant specialists in their field for ME patients.</i>
136	<i>immunologist and endocrinologist plus infectitious diseases</i>
137	<i>Not regular dietician, but someone with far more advanced and nuanced knowledge of diet, intolerances, etc - and also practitioner with understanding of environmental allergies and intolerances.</i>
138	<i>Patient input</i>
139	<i>Group for talking to others that are going through the same thing in my local area</i>
140	<i>Specialist nutritionist</i>
141	<i>Specialist trained GP</i>