



YOUR EXPERIENCE OF ME SERVICES



Survey report by
#MEAction UK

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APPENDIX 3

Appendix 3 - Comments from respondents who had not attended a specialist ME service

All comments have had identifying information redacted.

1	<i>Non available in my area. Left to own devices</i>
2	<i>Where I live there are no services for me/cfs sufferers. You are left on your own to manage it</i>
3	<i>The service said if you miss an appointment you will be discharged as 'you are not ready' for their help. Not many M.E. (Especially severe) would be able to complete it. This was St Albans.</i>
4	<p><i>I was given contradictory advice.</i></p> <ol style="list-style-type: none"> <i>1. First a GP told there was nothing wrong with me but anxiety.</i> <i>2. Next a different GP agreed with me when I said I thought I had fatigue - he told me not to push myself and I should make full recovery in a few months (5years ago).</i> <i>3. Then he referred me for GET but physio said that I was too debilitated.</i> <i>4. Next I was referred to psychiatry but CBT didn't help me.</i> <i>5. The psychiatrist told me at first that I was doing too much, then later he said I wasn't doing enough, though I hadn't changed my activity level.</i> <i>6. My GP recommended pacing without giving me any guidance whatsoever about what pacing meant for me or how to do it in a real life situation.</i> <i>7. There is no specialist ME/CFS service anywhere near me. I wrote to my local health board and MSP about this lack and was told other disciplines would meet my need. After reporting this to my new GP in writing and my subsequently phoning she has agreed to refer me to neurology. Now I'm on a 6 month waiting list, and I've already been ill for 5 years, and virtually housebound in bed most of the day with very little mobility, suffering PEM most of the time.</i> <p><i>I do not feel I have been well cared for by the NHS in this respect, with practitioners having little idea how to provide an informed, appropriate or consistent service.</i></p> <p><i>I live in Scotland but I think the revised NICE guidelines will affect how NHS Scotland deals with ME/CFS patients in future.</i></p> <p><i>In my view there should be specialist services in all areas with informed and trained specialist staff. It goes without saying that there is an urgent need for biomedical research to replace the current emphasis on a flawed psychological model.</i></p>
5	<i>I was told by my GP, it wouldn't be worth referring me to our ME clinic as I knew more than they could teach me.</i>
6	<i>we have no clinics anywhere near us. Paediatrics follow Bath protocols</i>
7	<i>There are no ME CFS services in Scotland (apart from one nurse in Fife) but people are still referred to Bath clinic - our physio obtained all information to follow Bath CFS clinics protocol and advice (which was GET/Activity Management). Prior to this, lots of active physio, and psychology was prescribed. So although not in attendance at a clinic, the clinic principles and instructions are applied. We can't have had the only physio doing this.</i>

<p>8</p>	<p><i>When initially diagnosed, 14 years ago, I was advised to pace my activities (not an option given in your survey), however I wasn't given any further details of what this might involve, or what the consequences would be if I didn't pace my activities. My M.E. illness was triggered by a sore throat, followed by a bout of Erythema nodosum. Prior to it I was a very active 50 year old, swimmer, cyclist, hill walker, culture lover.</i></p> <p><i>I have since moved to another part of the country. My current GP has stated she doesn't recognise ME. I've had raised eyebrows and been ignored if I've tried to tell other practice GPs and nursing staff that I've ME and how this impacts on my health. To my horror, one even said they had heard that graded exercise could help. I have mild to moderate ME and my main symptoms are PEM, usually triggered most days giving me pain and difficulty in moving, visual blurring, sometimes headaches. Nonetheless, I keep mobile and toned by gardening and walking when I can.</i></p> <p><i>I have several allergies, including to penicillin, and mild asthma, but otherwise am well and on no medications, apart from an inhaler to use if needed. I'm 64, intelligent, articulate and had a successful professional career and have no mental health issues. However, I find the attitude and treatment by these health professionals is deplorable, deeply upsetting and highly ill-informed. It means, too, that I'm reluctant to consult my GP on any health issue which may arise, indeed, I dread having to do so. I would plead that an extensive education programme is undertaken to educate medical professionals to disabuse them of misconceptions about ME.</i></p>
<p>9</p>	<p><i>I am in the US. I was diagnosed by a retiring neurologist when he ruled out MS (via clear MRI). No other neurologist I've been to recognizes ME/CFS. My Primary physician tell me to rest and monitors me (office visits quarterly and annual bloodwork). I have steadily declined. to about 20% functionality. Very frustrated and ready to give up going back to doctors.</i></p>
<p>10</p>	<p><i>M.E. needs properly funded, to give the millions of us without any safe, fair, or educated options, a treatment that scientifically works, and does not detereriate health making symptoms worse.</i></p>
<p>11</p>	<p><i>No ME services! Physiotherapists are still pushing dangerous advice to increase exercise.</i></p>
<p>12</p>	<p><i>lets be not poked prodded and put throughhell only to be tossed aside by doctors</i></p>
<p>13</p>	<p><i>I was diagnosed in 1991 and no one had much idea about anything to do with ME or CFS back then. Since then I have managed everything pretty much by myself with help from family as any doctors I have seen just ask me if I am stressed and don't even seem to recognise I have an illness. To be fair I haven't been back to speak to many as I have 30 years of experience with the illness and they just tell me to have some counselling.</i></p>
<p>14</p>	<p><i>Three friends & colleagues who've been diagnosed more recently have really benefited from the knowledge that they need to rest in the first couple of years after diagnosis. They're all now back at work, because they got the right advice early on and prioritised their health above their jobs. Unfortunately, the majority of people get exactly the wrong advice, which is why most of us are so ill we will never be able to access work again.</i></p>

15	<p><i>More awareness/education is desperately required for medical professionals. My daughter has had CFS for 5yrs now and during that time she has been discharged because "she looked pink" and on another occasion her diagnosis was questioned based on her ability to attend an activities weekend on a school trip (the Paediatrician ignoring the fact she crashed for 2-3 weeks afterwards). I was told in front of my daughter "all teenagers get tired". One Paediatrician's idea of GET was to admit my daughter into hospital for 2+ weeks, force her to wake and be taken to her school an hour away by taxi and returned to hospital. I refused this treatment on advice from the TYMES Trust who told me this "treatment" could cause a great deal of harm to my daughter. One Paediatrician said she wanted to her to see a Psychologist because she could find nothing physically wrong with her. The Psychologist said she was a resilient child and had no need to see her again unless my daughter wanted to. After reassuring reports from other parents I am finally taking my daughter to the CFS clinic in Alderhey in October. Due to my negative experiences with Bangor Hospital, Gwynedd, I am not 100% confident about Alderhey and as said, it's only the reassurance of parents who have actually taken their children there that we're going there for help.</i></p> <p><i>It is vital that the medical profession becomes more aware of this debilitating illness, it can have a knock on effect on everything else. Only now after 5yrs is my daughter finally getting some proper support with accessing an education thanks to a fantastic CFS/ME Physiotherapist that recently wrote to the LA saying it's what she needs.</i></p> <p><i>Children especially are being let down by the system, it's hard enough witnessing my daughter live a half-life since the age of 9 but what's been the hardest is having to deal with the ignorance and apathy of the very people who I turned to for help. We need more research, it's time for the stigma to end.</i></p>
16	<p><i>The health care professionals do not understand this disease. They give the wrong advice to sick people and make them sicker.</i></p>
17	<p><i>Also have fibromyalgia</i></p>
18	<p><i>There are NO services that help ME doctors are ignorant of the illness at best and at worse imply you are making it up. NICE and the NHS are culpable in the distress and despair of people with ME who have no where to go. As for CBT and GET those recommending it should be struck off.</i></p>
19	<p><i>No services for ME in Northern Ireland is having a detrimental impact on people's lives.</i></p>
20	<p><i>There were no clinics when I became ill</i></p>
21	<p><i>Yes it's time doctors in UK cared more for M.E patients mine just just shrugges and says and I quote "what do you want me to do about it"</i></p>
22	<p><i>More knowledgeable professionals and less hassle what ME/CFS fallis into</i></p>
23	<p><i>Would be useful to have ME support services in NI!!</i></p>
24	<p><i>I was diagnosed with Fibromyalgia and Post Vital Fatigue \CFS. I was given a leaflet on Fibromyalgia and shoved out the door. My doctors have been unsupported other than giving sick notes. I am bed\house bound for a year now still with no answers. I am about to loose my job. I have become a shell of myself. 6 month waiting list to get to see someone from a CFS clinic. My partner is now my full time carer. There is no support or understanding from medical professionals. You are essentially left to rot. I have had to research things myself which is hard when you are brain fogged. I am having to fight for PIP and Universal credit. I don't have the energy to have to keep fighting to be heard or get help. This condition makes you suicidal, when will professionals listen and care again?</i></p>
25	<p><i>I was instead sent to a general CBT course in pain management. This was appalling and of no use. ME/CFS services for adults are not available in my area</i></p>

26	<p><i>I haven't attended a CFS clinic because they didn't seem to have any in my area when I was diagnosed. After a few years and a couple of really awful encounters with clueless "professionals" I learned that, apart from a tiny number of exceptions, "experts" were best avoided. I have been very careful to stay well away from clinics. From what others have told me, as far as I can tell these clinics do nothing that a sympathetic GP and a handful of info leaflets can't; and those are the good clinics.</i></p> <p><i>in fact I found that one of the worst and most vociferous of the "experts" I had the misfortune to encounter actually had a financial interest in a private inpatient facility. I have no doubt his attitude and subsequent letter to my GP was more about the loss of earnings to his clinic (courtesy of my employer's insurance company) than any interest in my health and well being. All I was to him was a cash cow, simply there to be used to further his own interests even at the expense of my own.</i></p>
27	<p><i>I have been ill for 19 years. I have had no advice from any medical professional on how to deal with ME, only treatment for symptoms not related to ME. 19 years of medical neglect and not being taken seriously.</i></p>
28	<p><i>I'm based in central Scotland (near Perth) and as such, no clinics are available to me. Knowledge is very limited from those who I have seen (Dr's and Occupational Therapist) and for the most part, I have just been left to work things out and research for myself. My current Dr is/was great for providing sick lines (for DWP, currently waiting to hear back on my mandatory reconsideration), pain meds and is sympathetic, but there is very little else she is able to offer me.</i></p>
29	<p><i>i was unable to physically get to a clinic, i have been ill for 19 years, I have attended pain clinics and did the lightening process but have had little support or useful help from the NHS</i></p>
30	<p><i>I had to see a private consultant to obtain a diagnosis as no specialist service available in Scotland. GP referred me to a psychiatrist (2 year waiting list) and for CBT (useless). I am not being followed up in any way by anyone at present.</i></p>
31	<p><i>We need more specialist services who look at the whole picture not just psychological.</i></p>
32	<p><i>My GP originally thought that I was experiencing bog-standard burnout from s punishing work and exercise routine, hence why they initially advised me to take it easy with the expectation that I would be 'back to normal' in a matter of months. After my diagnosis (after 7 months) I never received (unhelpful) GET or CBT recommendations, but nor have I received much helpful advice (I've never been referred to s specialist, have met with consultants who have had to Google ME/CFS, have been told my GPs and pharmacists that my condition is psychological in origin, have been told that I should stop taking supplements to remedy my evidence-based defects, and was once informed that if I just engage in mindfulness practices I'm sure to be fixed).</i></p>
33	<p><i>My GP refused to refer me to the local M.E clinic - told me to google it instead; it would be just the same help / advice I'd get.</i></p>

34	<p><i>I was diagnosed in 1993 in England, UK, before there were any specialist ME/CFS clinics. My local specialist clinic is only for mild-moderate that can attend the hospital, only offer 4-6 sessions of CBT designed to help the patient 'adjust' to living with ME then discharges them back to their GP. So I have never been asked to undertake any GET or CBT specifically for the ME.</i></p> <p><i>Different GPs refer to my condition as either ME or CFS (some insist on calling it CFS) so I ticked I have been diagnosed with ME/CFS.</i></p> <p><i>I was originally diagnosed by a chest consultant (presumably because I could link the onset to an upper respiratory infection I had had 18 months previously). I was not given any management advice but was told that all the patients he had seen with this condition had got better within 18 months. He seemed unaware that I had already been ill for this time. Telling me this in front of an unsympathetic husband meant my home life became more difficult. I had 2 young children (pre-school age) and my (now ex) husband refused to help out with them or any housework - he felt I should be able to do this as I was not working outside the home at the time. So, the lack of advice to reduce activity was very harmful for me, but I cannot reflect this in my answers to this survey.</i></p>
35	<p><i>Am a UK ME sufferer in Scotland, there are no ME clinics or services</i></p>
36	<p><i>I was actually advised to do more on good days and less on bad days but there wasn't an option that fit</i></p>
37	<p><i>There are no ME/CFS services in my area. Also ME/CFS IS NOT BELIEVED BY ANY OF THE MEDICAL PROFESSIONALS IN MY AREA.</i></p>
38	<p><i>I would just like to add that as a former Psychiatric Nurse and a sufferer of M.E. to varying degrees since 1986 and being involved in M.E. Support Groups in the past.</i></p> <p><i>I have followed the CBT debate involving M.E./CFS treatment and guidelines and having retrained and taken a CBT course online and worked voluntarily in this field i would say that CBT is only useful in helping M.E/CFS sufferers with the psychological problems caused by their condition but not through Graded Exercise Programmes.</i></p> <p><i>If this approach is offered then I would avoid it like the plague.</i></p> <p><i>When I was diagnosed with M.E. in 1988 approx I received good advice from my GP and the M.E. Association and my experience has being to follow the good and ignore the bad.</i></p> <p><i>Also that everyone is an individual and what works for one may not work for another. It's a question of taking good advice and learning as much as you can about the condition and what works for you.</i></p> <p><i>Thanks</i> <i>Gary Tams</i></p>
39	<p><i>I feel it is important for those diagnosed with ME/CFS not to be forced into over exerting themselves. It is better for them to find the pace of life that best suits them, and to try living at this pace. They need to try to stay as fit and healthy as they can, slowly trying to work their way to feeling well enough for some semblance of life, and not doing too much, as this can push them over the edge into a dark hole where even undrawing curtains can be a struggle.</i></p>

40	<p><i>I was referred to a clinic in a town which was about a 30 minute drive from me. They only offered CBT groups, which I knew would not have been helpful since I am a Clinical Psychologist and understand CBT very well.</i></p> <p><i>The location of the clinic was also an issue as I find driving longer than 10 minutes makes my fatigue worse.</i></p> <p><i>I had previously tried an extortionately expensive private treatment for ME called the 'Lightning Process'. The therapy consisted of intensive introduction to cognitive restructuring and its benefits and the actual technique consisted of a combination of positive thinking and NLP. I did not find this treatment helpful, as it is clear to me that it is not my negative thoughts that are causing the symptoms. Although some people benefit from the Lightning Process, I believe it is a placebo effect. I have come across anecdotal evidence that CBT & the Lightning Process have made some people with ME worse.</i></p>
41	<p><i>I refused a referral to a ME clinic, as GET and CBT were all they could offer along with 'group' sessions. Didn't feel appropriate or that it would help me.</i></p>
42	<p><i>I did my own research and found guaifenesin, lost 80 lbs by walking at a leisurely pace each day. I do Pilates which helps enormously.</i></p>
43	<p><i>Doctors must be educated about ME. Their advice made me more ill.</i></p>
44	<p><i>The consultant I saw told me there was nothing she could do for me. Not helpful at all.</i></p>
45	<p><i>I did NOT follow my doctor's advice about exercising more, but that option is not provided. Hence, my answer to question 2 is inaccurate. Thanks</i></p>
46	<p><i>All children diagnosed/suspected with CFS/ME should be given immediate access to CFS clinic for advice regarding the importance of rest and the effects of PEM and help with handling school etc. Stop terrifying parents and children with the threat of GET and pushing on throw it does nothing except make the children worse</i></p>
47	<p><i>I have been struggling to find exercise that would be sustainable but I never improved and I was always left completely exhausted and nauseated. This was when my diagnosis was only Fibromyalgia. Once it was recognised that I also had CFS/ME I understood why. Having read a research article that explained that the muscles of CFS sufferers were failing to take up glucose during even normal operation, I now wonder how many of us have now deteriorated hugely after being advised that exercise will make us fitter. Physiotherapists never listened and I'm sure they thought we weren't trying. Changes in my tastebuds each time I have a flare, which seems to be weekly, sees me craving sugars and fats, which has ruined my diet after having lost 4 stone. I would like to know if there is any research into this.</i></p>
48	<p><i>I was very lucky in that I paid privately to see a visiting consultant who has an intimate knowledge of ME . Had I to rely on the advice of GP /Physio I may have faired differently.</i></p> <p><i>I did attend 2 sessions of hydrotherapy about 5 years post diagnoses and this resulted in a deterioration of my symptoms from which I have not recovered.</i></p>
49	<p><i>GP need more info on managing the condition without harming patients. Pushing through the fatigue has caused me harm.</i></p>
50	<p><i>I am glad to have been diagnosed by my GP long before the use of CBT and GET. This was at a time when a GP knew you and your family, and he recognised that I was ill with what he called Post Viral Fatigue Syndrome. He was supportive but left me to research the disease myself. I read library books and decided that pacing was the most sensible approach.</i></p>

51	<i>The lack of knowledge and help for this condition from all GPs I have seen means I have had to manage my own illness from day 1 to day 11,750. The lack of even basic knowledge of the condition throughout the health service has impacted on my fundamental care during pregnancy and eye operations. It has also greatly impacted my daughters health as the health service were equally slow to diagnose the same condition in my daughter over 10 years later.</i>
52	<i>We need research specifically on heart rate monitoring using a chest strap to stay below AT but also using zones, daily averages and resting heart rate .</i>
53	<i>I live in an area where there is no me cfs clinic. I cannot be referred anywhere I am at a dead end despite living less than 7miles from Scotland's biggest city. It is disgraceful</i>
54	<i>I was diagnosed by an ME/CFS specialist, who was very nice and understanding, but she pretty much said there's no treatment or cure, good luck.</i>
55	<p><i>I became ill in 1986. An article in The Observer (June, 1986) allowed me to identify my illness. I wrote to my GP saying I thought I had this. He came to see me, extremely angry, said he thought I was depressed. As I was running a mental health centre, and also had had experience of psychotherapy, I told him how to diagnose depression (low mood, loss of appetite, early waking, exercise improves mood) and that I had none of these symptoms, but did experience muscle failure upon minimal exercise and in general felt really awful. He handed me over to another doctor in the practice, who agreed that I probably did have ME, and that as there was no technical diagnostic test and no effective medical treatment, it made sense for me to just go home, rest, and ask for a sick note when I needed it. I resumed full time work after three months, using a wheel-chair, physical assistance to get to meetings, a PC offered from the finance department so I could lie writing reports with the keyboard in my lap and the monitor beside me. Also flexibility to go home and to bed after meetings and write reports when I felt able. Also had a telephone allowance so could spend a day in bed organising meetings over the phone. My illness improved, and has fluctuated over the years...never deteriorating into severe ME. I am now 84, spend a lot of time in bed, still able to write articles and study, with limited ability to do physical tasks. It seems likely to me that this questionnaire, requiring attendance at an ME/CFS clinic, nearly all of which use the BPS model, is likely to have built-in bias. I am aware that NICE are determined to find some way to include increasing activity as the main focus of management...despite knowing that increasing activity makes patients worse.</i></p> <p><i>The IOM report states clearly that ME/CFS is 'not psychogenic', so there is no role for psychiatrists or people dealing with mental health to be on the Review Committee. It also states that the defining characteristic of this disease is that 'exertion of any kind - physical, cognitive or emotional - may adversely affect many organ systems...' in the final sentence before recommending the name 'Systemic Exertion Intolerance Disease', making it clear that 'Intolerance' implies actual damage,('adverse effects'), not 'hypersensitivity'. Psychiatry and the BPS model have no place in the creation of guidelines for this disease.</i></p>
56	<i>There are no ME services in Northern Ireland especially for the bed bound. We muddle through with GP care only</i>
57	<i>I had to have cat scans and MRI scans to prove why I was ill. Also treatments to get rid of yeast overload</i>
58	<i>When diagnosed I wasn't offered any meaningful advice or support or referred to a specialist service. I was merely advised to reduce my working hours if possible.</i>
59	<i>I haven't attended because there is no such service.</i>

60	<i>My diagnosis was delayed years as not taken seriously by GP ... health declined significantly due to this.</i>
61	<i>Yes. I have never had any decent advice, treatment or information since onset in 1991. I wasn't even diagnosed for 12 years - I had to become too ill to work before anyone imagined I might have a problem.</i>
62	<i>I was told by the GP there was no such thing as a clinic or professional to see regarding ME.</i>
63	<i>The 3rd question is closed, the methodology may lead to Criticism that your survey is biased.. and may struggle to pass peer review..</i>
64	<i>I was later directed to a voluntary organisation, Westcare (in the late 90s in Bristol) and found that useful.</i>
65	<i>Yes, people should be told to go on long term disability and to stop working, exercising, doing chores and rest. They should be told that it is serious especially in the beginning and that it isn't in your head. I also feel that antidepressants helped me 3 yrs later and today. Plus, that researching ME/CFS is best with Phoenix Rising forum and Facebook pages of those suffering.</i>
66	<i>No assistance has been provided by my local health authority.</i>
67	<i>I was first very ill following a virus in 1988. I was too ill to continue working as a Special Needs teaching assistant. The GP was supportive and believing but couldn't offer anything except advice to rest. I paid to see an immunologist and after many tests to rule out other possibilities he agreed with the GP and said I seemed to be coping quite well and should continue resting and gentle activity. I've always met with kind sympathetic GPs and have been treated for symptoms that have arisen but I haven't been offered any specific support for ME. GPs' comments typically are that I probably know as much about the illness as any special clinic!</i>
68	<i>There are no clinics available in Wales. I would have appreciated some help, for example to learn pacing.</i>
69	<i>I was not given any option to attend special CFS clinic (mine would be in Edinburgh). Psychology dept. in Livingston was the only place I was sent to by my GP. They said they could not help in my case, but offered antidepressants and I was given quite a useful booklet on Pacing and Stress.</i>
70	<i>Yes, since my initial diagnosis nearly 7 years ago, my CFS has been completely ignored by the GP. It is never referred to and I have been given no support at all despite it having a catastrophic impact on my life.</i>
71	<i>ME services are awful awful awful. Made my child worse from poor advice</i>
72	<i>I have never been offered a place a a ME clinic</i>
73	<i>There is no provision of any help for those who are bedridden with ME or housebound and too ill to attend a clinic. They are like forgotten people with no support from the NHS whatsoever. This needs addressing.</i>
74	<i>I have lost 16 years of my life with no help or advice. This disease is a living death sentence. We are being left to rot. The medical 'professionals' have a lot to answer for. Time will tell.</i>

75	<p><i>I didn't attend a clinic because the only clinic available in Leicestershire at the time (~ 2006/7) was a CBT clinic and my M.E./CFS was not considered severe enough to attend that clinic. However, the psychologist assessing me who led that clinic did refer me to her other clinic for depression, as I had also developed this alongside my M.E./CFS. I found the CBT helpful for my depression.</i></p> <p><i>My G.P.s reaction to diagnosing me with M.E./CFS was along the lines of "I didn't believe in M.E./CFS until recently but now I do. I wish I could diagnose you with something else, as there's nothing more I can do for you with a M.E./CFS diagnosis". I haven't really sort any further help with this aspect of my health via my GP or other NHS services due to this.</i></p>
76	<p><i>I did attend a clinic but the consultant running it said my symptoms didn't exactly match CFS criteria in that I was cognitively very sharp - just unable to function and unable to walk/exercise due to pem. Hence I fell between the gaps and no help or support available at all on nhs</i></p>
77	<p><i>no</i></p>
78	<p><i>I just have had no advice or support what so ever left alone to help self help mental health teams did help at first dreadful</i></p>
79	<p><i>I haven't attended a clinic because there wasn't one in Northern Ireland where I live.</i></p>
80	<p><i>Lack of help and support from NHS</i></p>
81	<p><i>I would have liked to have gone to a clinic, but there is not one in wales,uk</i></p>
82	<p><i>Yes. I was given a diagnosis of me/cfs 34 years ago. Then the DWP told me at my last assessment for PIP, a year ago, that all my papers were missing and that anyway only the last 6 months of information about a patient was admissible evidence. This meant my UK doctor wouldn't commit to the diagnosis. I submitted the papers I had, they were deemed not enough evidence even though I had been receiving benefit help all that time. The doctor said and I quote "I can't know what you are like when you are at home all I can see is how you are now here at the surgery", she even became angry with me when I started to cry. I no longer trust any doctors, I have had no help for 34 years. I filled in this form in a state of rage.</i></p>
83	<p><i>I needed to be told that this is a long term illness which doesn't go away, and to rest, manage my activity levels and make life style changes to accommodate my reduced capacity. Instead I went back to work, relapsed and never recovered.</i></p>
84	<p><i>i have attended pain management but am currently on the waiting list for fatigue services. It would make sense to have a clinic where both can be addressed. I have a dual me/fibromyalgia diagnosis which is common.</i></p>
85	<p><i>My answer above was based on my initial GP visit. I've never been given an NHS diagnosis or been told how to manage my illness - everything else learned I've found out myself and funded myself at considerable expense. I'm lucky to have a supportive employer which means I've been able to continue working part time and can therefore fund these interventions BUT I know that many are not that fortunate and are stuck with an illness they don't understand how to manage, with virtually no support from the NHS and no ability to pay for private support. The NHS needs to provide a consistent and multifunctional approach to diagnosis and management of the illness. At the moment this is sorely lacking, leaving many in misery.</i></p>

86	<i>I was told exercise was the only way forwards by a GP who had been to a seminar organised by Prof Michael Sharpe. So I went swimming ended up in hospital I was bedbound for 18 months rather than accept what had happened to me was because of the advice given to me to exercise my GP practice tried to have me sectioned. I was lucky at the time I knew of a ME specialist at Sheffield as an Immunologist called [redacted]. Those docs from ME clinics disappeared and were not physically possible. The only docs there if there was one was a psychiatrist. When will NICE start to put this all right. My experience was late 80s early 90s</i>
87	<i>I was told to make sure I walk to and from the local shop daily, it's half a mile from my home, even if I had to force my body, I had to make sure I kept up this exercise to prevent any deterioration/de-conditioning of my body. It was this, that led me from being a moderate sufferer to a bed bound severe sufferer. I was completely given the wrong advice, I should have been told to rest, that this is not like any other illness, you cannot beat it by forcing your body to continue doing duties or exercise that you did before getting M.E.</i>
88	<i>Sent to rheumatology because there is no ME clinic in Glasgow</i>
89	<i>I wasn't told there were any specialist services by the neurologist or by my GP, this is despite many appointments and me being desperate for help to recover. I have been ill for 3 years now and it's only through my own research that I have learned about these services. I also believe that had I been told to stop working and rest properly when I was initially diagnosed that my condition wouldn't have been as long-term as it has become.</i>
90	<i>Your questions are too limited. I was DIAGNOSED at an ME/CFS unit ten or fifteen years after complaining of symptoms and being treated as a malingerer by GPs. The assessment of malingering is still on my records and unduly influences specialists dealing with other medical conditions to this day. However, after diagnosis at the clinic, I was refused treatment, monitoring and support by the clinic or anyone else, apparently because of a funding dispute involving my local health authority. My condition has deteriorated as a result, I cannot cope with the physical and financial demands of living in social accommodation which is not suitable and I am being evicted. With no legal redress.</i>
91	<i>I have found it very hard to find people in Norfolk that deal with me, I have no help with me since 2003 when I was first told and doctors are no use in dealing with me so I have been on my own.</i>
92	<i>There is no ME/CFS clinic available to access in Tayside. That service doesn't exist.</i>
93	<i>I want doctors to say " We don't understand how this illness works because we haven't done enough research. You are clearly suffering and I will do my best to alleviate your symptoms if possible. I fully support patients becoming experts in their own illness. I won't be offended if you know more than me."</i>
94	<i>After 20 yrs with ME and still housebound... I was admitted to hospital with suspected DVT... the doctor had never even heard of ME... asked what it stood for</i>
95	<i>I did attend graded exercise and Cbt clinics, both an utter waste of time. Neither professional had a understanding of ME and very dismissive of it.</i>

96	<i>I have approached and been approached by local clinics but have chosen not to go after finding they have been run by psychiatric teams and around the GET/ 'curative' as opposed to supportive CBT model. The literature published on their websites make it very clear they follow the outdated/ discredited models of the disease, they are not aware of the latest biomedical developments and don't engage in management techniques or sanction things which patients find most helpful such as pacing. Their literature is often condescending, offers unrealistic overviews in regards to recovery/ management, and is very off putting in that regard as well, especially as a long term patient. While I have frequently felt that I could use more practical support in terms of occupational therapy, and possible even more suitable forms of physio etc., to improve function, minimise symptoms and provide support etc. I have felt utterly unable to reach out and access services in case I wind up getting pushed too hard by people following an extremely outdated/ discredited model of the disease. The approaches of ME/ CFS clinics in this regard are therefore directly responsible for me being unable to make use of them as a long term, very severe and bed bound/ housebound patient who is often in need of their support.</i>
97	<i>I have never been advised of a ME/CFS service. I was told by my GP and Rheumatologist that there is no treatment or care for my disability and I need to manage it myself! This I have done by using information that I have obtained from the internet and other people's experiences who have the same disability.</i>
98	<i>I wish there had been specialist services available to me. I was left totally alone to cope.</i>
99	<i>There aren't any ME services, in my area</i>
100	<i>Please find a cure, protocol, medication to support, alleviate, rid us of this horrible affliction. I just want my life back and to be the mother my child deserves. Getting so deeply depressed about the shadow that I am these days</i>
101	<i>I would like to be seen by a professional that knows about this illness</i>
102	<i>I have been told repeatedly by 5 different GPs and a neuro that I have a psychiatric illness - depression, somatoform disorder, hysteria. No investigations were made into the symptoms I reported. These were ignored.</i>
103	<i>I wish health care professionals understood invisible disabilities as we have good phases as well but they don't see us in bed.</i>
104	<i>Health professional need to be educated on how PEM affects us, don't advise us to increase activity levels, believe us when we say we are very sick despite looking okay outwardly as they don't see the energy we've conserved just to see them and don't see us collapse in bed at home</i>
105	<i>I was given the chance to attend sessions run by OT's at Wareham Hospital in Dorset. This was for 6 sessions just after diagnosis. These sessions used the CBT and GET method of dealing with my condition. Following the 6 sessions I have had no follow up or further support from this service. That was 4yrs ago. Any slight improvement I have managed to make has been purely through my own research and perseverance to improve my quality of life. The support offered by the NHS I feel is outdated and not person-centred in any way. The fact that there are still Dr's who question the true existence of ME/CFS is troubling.</i>

<p>106</p>	<p><i>Due to deteriorating more severely after medically advised early increase in exercise, i became permanently bed bound and have continued to deteriorate over the last 30yrs as a result.</i></p> <p><i>Also due to lack of understanding, compassion or any helpful kind of support, especially biomedical, my whole life quality is sub human. I am shocked at the damaging neglect and aggressive interventions and long drawn assessments public agencies have pushed me into (+ Many other ME Sufferers) .</i></p> <p><i>Agencies such as NHS, Social Care, Dept of Work and Pensions and , Social Housing . I have been left deeply Permanently Traumatized as well as physically damaged and deprived of basic human needs.</i></p> <p><i>Equally shocking is that this is still allowed to continue after several decades due to lack of Government Biomedical Funding Both Nationally and Internationally.</i></p> <p><i>I Hope Medical Authorities that have had and continue to have the power to change this, will start listening and believing the biological evidence and ME Sufferers especially the most Severe who know what support is helpful and what is damaging and what is prolonging our suffering and deteriorating our condition and lives.</i></p> <p><i>Not to mention the painful effect or has on anyone who cares about us having to helplessly watch us wither away in slow agony.</i></p> <p><i>It is unnecessary as an great increase in Biomedical Funding and stopping Exercise programmes and Psycho suggestion Treatments that undermine our Authenticity, would vastly quicken helpful treatments for us.</i></p> <p><i>It has been neurologically painful and debilitating compiling my comments here but worth the cost to add my voice to truth which will win out in the end, if not for me , at least for those to come.</i></p>
<p>107</p>	<p><i>The ME services in Birmingham involve a referral to Psychiatry which is useless and demeaning. My GP just shrugged when I told her. I paid privately to see [a professional] at the hyperbolity clinic in London and he told me I had CFS, Mine is related to hyper mobility but I have been met with ignorance at best. The most sympathetic was the podiatrist at the Orthopaedic hospital. Rheumatologists were rude so I got upset, so they diagnosed anxiety! The best treatment has been with an osteopath who follows the Perin technique - but this has cost me a lot of money though has really helped. He viewed my symptoms as ME. Most NHS professionals are not interested in experts such as Dr Sarah Myhill - and they are not interested in the extensive research that ME patients often do. I continue to be dismissed. My ME symptoms that include gastro issues and POTS like symptoms are generally put down to anxiety. Anxiety increases when you are not believed. Birmingham ME services need to be transferred to Neuro/immunology when they belong.</i></p>
<p>108</p>	<p><i>I have not attended a clinic just gp as ill in 1996 as severely affected. I had recovered fully from PVFS in previous years and thought it was same again, and did same things as for PVFS. After 4 months I had asked if it ws ME but gp said I wd be worse if it was ME. After 7 months, in 1997, another gp said cfs as ME had just been renamed but no advice. I got worse, and vided increasing activity a bit more weekly I had already discovered from experience by then about PEM and knew energy was sum total of all energy used in the day so did not walk more each week and explained that to him, but I didn't realise standing still was so dangerous and that so many pwME have Orthostatic intolerance and relapsed badly after doing so, first holding ladder, then while still unwell after that, at a family funeral. Have been severely affected since.</i></p>
<p>109</p>	<p><i>I have tried pushing through my symptoms but it doesn't work I can make myself I'll for a week for just one extra 10 minutes spell of exersion after I reach my limit you need to think again just because you can't pinpoint a cause of this doesn't mean it isn't real it simply means you haven't got a suitable sensative enough test.</i></p>
<p>110</p>	<p><i>The only advice I've been given from my Dr is to take vitamin D & zinc.</i></p>

111	<p>Was originally told it was all in my head / depression / conversion disorder when could not walk anymore by GP when I was 17/18 and was given antidepressants which I don't think I needed, I had a lot of viruses in a row (about 15-20), lymph nodes swollen up, hurt and stayed up for a couple of years and still hurt, I also had a lot of stomach infections in a row and ear infections and had to sleep 18 hours a day and could not do anything for myself. saw neuro who found nothing wrong but they did not do ANS testing (could have had POTS syndrome) so they sent me to psych (was training as a dancer at the time and super active then I got to sick to walk) was diagnosed with ME by psych who told me I was not depressed but actually sick and ended up 95% bedbound as fatigue was so bad. Also have HSD and discolorations, diagnosed at 13 (cause pain, fatigue) also got diagnosed with POTS at 35 about 20 years after symptoms started. Went back to psych for C-PTSD problems (I think it adds to fatigue and takes up a lot of mental energy but it's a major cause of it been so bad that ended up bedbound) This psych told went through all my old medical notes and is 99.9% sure ME was triggered by mono/Epstein-Barr and I have vagus nerve damage. I think (not a pro but lots of experience) that ME and POTS are separate but can have both and anyone with ME/CFS should be tested for POTS and if your diagnosed with ME/CFS it could have a different cause but you are actually sick :(</p>
112	<p>I have had no support whatsoever my GP's prescribed Amitriptyline for over 20 years until I discovered you're not supposed to take it for more than 9 months because it causes heart damage when I asked my GP why he hadn't warned me he said 'It didn't occur to me till you mentioned it' Another GP after discussing the fact my heart consultant had told me I have the heart of a Heroin addict while discussing depression went on to offer me Amitriptyline and another antidepressant that I'd tried to kill myself with in the 80's She handed me a computer print out stating the damage caused. I also discovered that the NSAID's I'd taken for decades actually cause pain if taken for more than 3 weeks - I was bedridden with pain for years but was able to function again when I stopped taking them.</p>
113	<p>I was treated by my Rheumatology dept and referred on to hospital services. Physio, Hydrotherapy in hospital pool. Medication Duloxetine was a massive help. Pain clinic, pain management program was a real help. I was fortunate to have a great team of medical staff who helped me to build back some strength and be better than I was. Still unable to work, all priority of pacing applies now in my 9th year of this awful illness. I think more awareness and quicker diagnosis is needed. Took 2 and half years for my diagnosis which I was housebound by then. I went from a very active person catching a cold and never ever regained my old self back.</p>
114	<p>My teenage daughter has been ill for two years. It started with an infection which was never properly diagnosed or treated. The GP took numerous blood samples and prescribed various courses of antibiotics, none of which were successful. After a three months, he referred us to the paediatrician. Four months we were informed of the diagnosis of CFS and told to "keep it till it gets better". At that point, my daughter could attend school for perhaps one afternoon a week, and we were encouraged to build up to more. This brought about severe post-exertional malaise, as did graded exercise sessions with a physiotherapist. Sessions with CAMHS, when she was well enough to attend, eased her anxiety but had no impact on her physical health. At no point was my daughter referred to infectious diseases, there has been no stool test to look for parasites, no contact with the paediatrician beyond six monthly appointments. He said to us, "you know more about this than I do", but did not feel the need to refer us to anyone else with any expertise or experience in paediatric ME/CFS. After eighteen months of illness, we sought alternative, private help. A change of diet and supplements made a significant improvement in levels of fatigue until the sudden onset of new symptoms, muscle spasms, dizziness, loss of mobility and muscle strength in her legs. She is now bedridden and needing a wheelchair. We attended Forth Valley Hospital twice, once via blue light ambulance, and were told "these things happen" and sent home. It took much persistence on our part before she was finally given an MRI scan, which was clear, and we are now waiting for blood test results. At no point in this journey has our family received any support for living with a deteriorating chronic health condition and we have to fight every step of the way to get our daughter the medical help she so urgently requires. She has lost two years of her</p>

	<i>schooling and is rarely able to leave the house. For us, receiving a diagnosis of ME/CFS has been the equivalent of being stuck in a cupboard and left to rot.</i>
115	<i>General lack of understanding amongst GPs. With years of research, it feels like I have more understanding of the condition and have developed ways of managing my condition better than any medical treatment or programme has been able to offer in Wales.</i>
116	<i>I have seen GP's who eventually diagnosed ME. I was referred to hospital consultants for GET (Graded Exercise Therapy) and CBT (Cognitive Behaviour Therapy). GET made me worse and I had to stop. CBT had no effect at all. So I'm just given lots of drugs to help with the symptoms.</i>
117	<i>I haven't attended a clinic because there isn't one in my area. I'm virtually housebound & travelling causes me to deteriorate. With the lack of research, I feel I am the most qualified to manage my symptoms as GPs can't work miracles. I use pacing. This is the only strategy that keeps me from being bedbound.</i>
118	<i>I have had NO support regarding my M.E. In fact I've been through the worst times of my life as most 'professionals' don't even believe it's a real illness, they imply often that it's all in my head. I've received ridicule, abuse, neglect and truly have been left broken. The so called people that are meant to help, have made my life a living hell and pushed me to the point of a complete breakdown. I'm barely hanging on and have been left to rot, I have NO support, NO help, NOTHING. I live alone 24/7, see NO people and I'm barely surviving. There's very little point me even being here, I have NO life, I just exist and don't feel like I'll be able to even do that for much longer.</i>
119	<i>All my health issues either just get written off and lumped in with ME/CFS and therefore the GP has no advice to add. And so I just keep getting worse.</i>
120	<i>Ten years ago when first diagnosed, I was refused admission to the local ME/CFS clinic as they said I was over the weight they accepted and was told to lose weight before they would see me. If I could exercise to lose weight (which I would've loved to do), then I wouldn't have ME/CFS. So 7 years later, managing my weight that I only gained 4 pounds over that time and my GP telling the clinic this, the clinic denied me any help again. I have been completely ignored by my local ME/CFS clinic but thankfully I have a very supportive GP (not the original GP who diagnosed me) who helps me as much as she can. ME is devastating and being abandoned by those who are supposed to help and support contributes greatly to the depression that I feel with this disease.</i>
121	<i>I became ill 17 years before the guideline like so many with this illness without early diagnosis and guidance to stop activity I tried to return to normal activity levels following the initial illness building up slowly and gradually got worse and worse until I stopped. My GP has basically left me to get on with it ever since providing medication to treat symptoms where it was possible to do so. I have found Amytryptiline 10ml before bed helps with sleeping and therefore pacing. I consider myself fortunate to have a GP that didn't have NICE guidance to go on but just did what he could to help.</i>
122	<i>Since being diagnosed at Maudsley Hospital, London in 2011, I was refused treatment by them because my local CCG refused to pay for the service. I have therefore received little to no help or guidance with this illness and am angry and disgusted at the lack of funding/research/help that I and hundreds of thousands in a similar position have received. We have been singularly failed.</i>
123	<i>Initial GP tires for unsuccessful treatment (no consultant input after diagnosis) in England, but now nothing further in Scotland</i>

124	<i>I was diagnosed in 1996, and the GP that came to my bedside was very experienced (just retired and working as a locum) and recognised the physical symptoms I was showing of a neurological condition whilst I was lying in bed. I worked at a residential school with children with cerebral palsy, and he was the GP. He pointed out the similarities and said to do no more than 19% in a month than I could do now. However, with no social care support this was impossible.</i>
125	<i>The 'treatment' from the NHS & Local Social Services, When U have "Chronic Fatigue Syndrome" &/Or Fibromyalgia &/Or M.E. is ABYSMAL!!... :(- MEDICAL SCIENCE SHOULD HAVE FOUND A GENUINE, PROPER CURE BY NOW!!</i>
126	<i>There were no services or help offered</i>
127	<i>The advice given by a health professional when I first discussed my symptoms was horrendous, unprofessional, ignorant, without knowledge of M.E., arrogant, uncaring, useless, rude and greatly worsened my health for many years and still does. The nhs health professionals ALL need retraining and educating properly in the treatment of M.E. They ruin lives with the lack of proper treatment and prescribing dangerous G.E.T. and C.B.T. Proper research needs to be done into the physical causes and symptoms of M.E. and an apology for the stigma caused by the nhs for people with the condition. Relevant medication for physical deficiencies should be provided rather than wrongly labelling people with Psychiatric disorders and mistreating them with anti depressants!</i>
128	<i>Took 2.5 years for GP to refer me to Fatigue Service, and now I have a 7 month wait for my appointment there.</i>
129	<i>I have had no help at all. GP 1. made it clear she did not believe me. GP 2. said I should develop a philosophical attitude and offered no help. GP 3. said there was nothing that could be done to help with sleep or any other symptoms. I was not offered an ME/CFS service.</i>
130	<i>I was referred to the CFS clinic in Haywards Heath, but was too ill to attend.</i>
131	<i>What services they are almost non-existent and even those that do exist are way over subscribed. These conditions are not taken seriously in the UK</i>
132	<i>There is no appropriate specialist that you can be sent too. The current set up is about GET & CBT which is not treatment of ME. Hormones like sex hormones, growth hormone secretagogues , low dose hydrocortisone. Thyroid meds, medicines for autonomic dysfunction, mitochondrial supplements & multivitamin powder and weekly immune globulin injections to modulate immune system make way more sense. Current treatment is no treatment. People have had brainstem encephalitis and encephalomyelitis with m.e.</i>
133	<i>The only help I've had, I've found for myself. GPs are not well enough informed. Apparently no specialist in central Scotland.</i>
134	<i>I have been ill for 32 years. There were no ME clinics then. My GP referred me to a immunologist who gave me the diagnosis.</i>
135	<i>I had to study and learn to be my own doctor after the disbelief, disrespect and stress causing abuse from NHS after a virus in 1980. Dr Sarah Myhill, a specialist in ME, now helps through her website and book. So strict Paleoketogenic diet and £150 worth of supplements and absolutely no exercise, ONLY I can work out how much energy I have to spend. For nearly half of my life I've been forced to protect myself from NHS doctors and narrow minded opinions, at times shocking.</i>

136	<i>There are no services or specialist in my area.</i>
137	<i>There are no clinics in Scotland and doctors are still taught that it's psychological.</i>
138	<i>Having worked in the NHS for 25 years, I lost all faith in many fellow medical professionals. The attitude to this illness amongst the majority of the medical profession is questionable to say the least. First do no harm? CBT and GET have done nothing but harm.</i>
139	<i>In my experience a whole foods, plant-based diet has helped reduce the severity of my symptoms.</i>
140	<i>I have never been offered despite asking, any clinics or other consultant referrals. My GP only offered exercise referral rehab scheme, forced me to take antidepressants, which i didn't want or need as otherwise would not see me. GP was following NICE guidance which is clearly wrong and highly harmful. I've had to do my own research and find my own help, paying for appointments that I can ill afford to do, since I was forced out of my job due to ME and being off on long term sick as no longer able to work full time and they were not prepared to wait to see if I might recover enough given time to work very reduced hours (my employer was the NHS!!!). I applied for and was refused DLA. The process was extremely stressful and tribunal a horrid experience. Clearly nobody believed I was ill, I was called a Liar by a representative from DWP sitting in on tribunal cases that day, an unreliable witness and nothing presented at the tribunal would change the option and decision of DWP. The system is a disgrace .</i>
141	<i>There was no specialist service available to me when I was most ill - it was an hours drive away and I couldn't travel. I was given a variety of different advice at different times over the 19 years I've been ill. The worst time was while at my illest (unable to function at all, helpless in personal care, confined to bed, unable to speak or chew) when my GP offered me a bed in a psychiatric ward. I'm so glad I wasn't forced to: it would have been catastrophic. In the 11 years since then I have slowly improved through my own persistence, research and trial and error.</i>
142	<i>No clinics in Scotland,training for doctors based on the most current bio medical research esp from univof Stanford,Columbia,caifornia and Harvard.the discredited PACE must be withdrawn.....what are the chances ...probably zero.</i>
143	<i>G.E.T and C.B.T being offered as a cure is incredibly harmful and ineffective- it needs to stop.</i>
144	<i>No services around where I live. Just been left to get on with it really, no input from various gps over the years.</i>
145	<i>My GP just said he could refer me to a neurologist. Been there done that. I've tried 68 different approaches so far, some running into thousands.</i>
146	<i>I was left to fend for myself.</i>
147	<i>The way children with ME are treated is a disgrace and professionals would rather fabricate statements educationally and remove actual medical information from medical records than actually help a child who is sick. The harassment a family gets in order to push the psychological agenda and ignore any biomedical evidence is a disgrace</i>

148	<i>I feel that another supportive approach needs to be the main treatment. Provide the care needed in the home,mental health support,alternative therapies,more tests for co infection,practical support like help to get to appointments or even just providing company for those of us on our own. More direct access to occupational therapy and medical aids without question. More funding to increase mobility with electric wheelchairs so we can still be included in the world. More support in education for children like my daughter who left school with no qualifications. Clinics that provide alternative therapies to ease symptoms. If we can't cure it or treat it then we should be helping people cope with it x</i>
149	<i>I have attended pain clinics all advising an increase in activity with terrible consequences.</i>
150	<i>I was given no advice, just come back in 6 months. I was not told that normal activity would cause deterioration and my family knew nothing about it. I did not get the help I needed and tried to continue looking after my family. As a result I got worse and worse and eventually collapsed. I was bedridden for many years and I have never recovered. I have never regained my ability to do day to day activities normally. I cannot walk anywhere and must use a wheelchair if I can manage to go out which is rarely as I have sensory overload. I am described by GP's as having severe ME and I have never been offered any treatment apart from antidepressants and painkillers. I have never been offered a visit to an ME/CFS clinic.</i>
151	<i>I have asked for a referral to the ME clinic on numerous occasions and it still hasn't happened. The referrals are made and then seem to disappear into the ether!</i>
152	<i>I was told to take antidepressants and given Amitriptyline which caused huge panic attacks and did nothing to help. All helpful treatments I've had to find in isolation, through my own research. My Dr. didn't even connect me to the local M.E. action group.</i>
153	<i>I was diagnosed in 1990 & within 6-10 months of illness start. It began after several bouts of severe flu which I rested insufficiently with & infection/ altered blood cell count still showed in blood tests. I was lucky to receive sympathetic treatment but still deteriorated & eventually had to seek medical retirement.</i>
154	<i>I was diagnosed in Australia where I am from. All doctors in the UK have been dismissive of this diagnosis. Pain management said without examination that I had fibromyalgia and told me to watch a video that told me I could control my pain with my mind. I haven't bothered to seek further medical attention as my symptoms are mild and it feels as though to do so would incur further medical dismissiveness and gaslighting. Unless I can see evidence of real change in the nice guidelines in diagnosing and dealing with this illness, I will not seek medical help within the UK for me/cfs</i>
155	<i>Not really other than I've had to work out a way to survive this illness by doing it on my own and finding my own way. Little or no help on offer</i>
156	<i>I do not have CFS/ ME. My 13-yr old son was diagnosed with CFS in March 2019 by a general paediatrician at an NHS Hospital. Whilst not able to offer any other service apart from two individual sessions with a psychologist and a support group for teenagers, the regular paediatrician appointments have been invaluable as he has been positive regarding prognosis and the concept of recovery. This has been incredibly important to us as a family, not least my son who is never in doubt that he will get better even if it takes time. The psychologist at the same hospital who was helpful in lots of areas felt that my sports-loving son should work on acceptance that he would have to learn to live with this indefinitely. This is not helpful for a 13 yr old and we rejected this idea. We have since been pursuing non-NHS CFS/M.E support which provides hope and belief in recovery. My son is now making progress and attending some school again as well as re-building his strength for sports. Thanks to the Optimum Health Clinic and Lightning Process we now know that he will recover.</i>

157	<i>All my GPs have consistently equated my fatigue/PEM with depression and their only recommendation has been to take/increase/change antidepressants. This has meant the last 30 years of my life has been a deeply frustrating and never ending round of antidepressant changes (as none produced any positive effect on my fatigue), serious difficulties with withdrawal and side-effects and all to no avail regarding the fatigue/PEM. CBT made no difference to the fatigue/PEM but left me feeling a bit of a failure as the psychologists view was that "this cure works" so the fact that it hadn't was down to me. I have more recently come off antidepressants, wear an activity tracker and heart monitor, learned to pace myself and rest when unwell rather than push myself and found a way of living which allows me some small degree of 'normal' life. I SO wish this approach had been available 30 years ago as it would have allowed me some small degree of normal working, social and family life rather than the never ending boom/bust life which was the result of following the GP advice of 'take antidepressants and push yourself through it'. To this day my most recent GP consistently still speaks of "THE diabetes" in one sentence but "YOUR me/cfs" in the next as a not-so-subtle indicator of which aspects of my health she is willing to be a partner in vs those she sees as entirely my responsibility (and choice in her view). It really is time to stop blaming me/cfs patients. And it's time to stop insisting it's curable by psychological treatments: it is not.</i>
158	<i>No Thanks</i>
159	<i>Although my GP has understanding and empathy with my condition I feel I am very much on my own for managing or ameliorating my condition, generally by reading advice given by ME charity and research organisations. I experience PEM after any level of exercise or general social activity. I avoid exercise because I know of its damaging impact on me. And as for social activities; I need to prepare, by resting for a couple of days prior to any social activity and plan rest time into my schedule for afterwards.</i>
160	<i>I was never referred to a ME/CFS clinic following my diagnosis at Newcastle Royal Victoria Infirmary.</i>
161	<i>I have been ill for 28 years, I live in Scotland but have NEVER been referred to any M.E/CFS services. I was just left to get on with it on my own.</i>
162	<i>There isn't enough understanding given to us in dumfries and galloway. Even trying to see a doctor is about impossible. They mess about with our meds and we have to plead for something that has helped</i>
163	<i>I did attend a Pain Management specialist in Leicester and the tests and referrals for other possible conditions was amazing. I was taught to do limited acupuncture on myself and found this very good short term. I was diagnosed 20 years ago by a Neurologist and was offered no help or follow up.</i>
164	<i>Yes I was diagnosed in 1992.in Sale Cheshire. My GP had just been on a ME course, exceptional when most people were calling ME yuppy flu!! I didn't get much advice other than drinking lots of just water to dehydrate me because that equated to energy. That worked and I never go anywhere without a bottle of water. At that time I could hardly get out of bed, my brain was fogged and I forgot how to make a cup of tea or remember the words of the Lord's Prayer, both things I do every day. I was at that acute stage for a few year's. I lived alone with no carer so it was hard. It took a year for my GP to diagnose my M.E by a process of eliminating other illnesses. After two years I was registered as disabled and medically retired from work. My condition still fluctuates between not being able to do anything to being able to go to get my shopping or visit friends. ME is a complex unpredictable and uncontrollable medical condition that covers so much of the bodies organs. Only a sufferer would understand what I mean. My only medication is pain killers. I have never been referred to an ME clinic even at my own acute stage.</i>
165	<i>NEVER been offered any support in 32 years</i>

166	<i>There is no consultant or clinic for CFS/ME in N.Ireland, I was originally diagnosed in Southampton and the service was excellent.</i>
167	<i>I was not diagnosed with cfs m.e. for 2 years. After telling my Dr how I felt ill the whole time I was at work and some days could hardly stand once I drove the 4 miles to work, he told me if I could work, I had to work. I now am disabled with p.o.t.s as well as m.e.cfs and have not worked in 5 yrs. The doctors at my practice admit quite happily they know nothing about the illness. My neurologist thinks there may be such a disorder, but he does not know. My doctors have been generally supportive but are ignorant of the symptoms of cfs m.e.</i>
168	<i>My own research was the only way to find out about CFS - no provision as recommended in NICE guidelines available to me. I am however extremely fortunate that I have a number of understanding GPs.</i>
169	<i>Marathon running to severe CFS</i>
170	<i>The doctor refused to acknowledge it was ME but advised looking on the AYME website. He contradicted himself every time we saw him. Eg. 'Write down your symptoms.' Took him a list of symptoms and it was very long. The response was 'you're focusing too much on your symptoms'. Refused to refer to a children's ME clinic. We emailed them and they wanted to see us. This took so long to sort out the age limit was passed and the clinic couldn't accept the referral. The doctor had no understanding of graded exercise. He thought increasing a walk by 10 yards a day was appropriate. In reality it was 1 yard a week. This long slow process doesn't seem to fit with current models of therapy.</i>
171	<i>I was diagnosed 30 years ago and at that time no referral or treatment was available. I had absolutely no support whatsoever and either blank looks or hostility from most medical professionals. However in some ways I was fortunate because I was not forced into any kind of treatment that may have exacerbated my condition or made it worse. My experience is that rest when I feel ill is essential, and that pushing myself into activity makes me worse both immediately and in subsequent days and even weeks. Forced activity is without doubt the worst possible thing I can do.</i>
172	<i>I have been severely affected for 28 years. My daughter for over 30 years, neither of us have been offered any help or support for our ME</i>
173	<i>I was bedbound for many years and found there was no help for the severely effected</i>
174	<i>A specialist or clinic is required in NI</i>
175	<i>I had not got any help from doctors for 3 years. Everyone said: go to the psychiatrist. awful</i>
176	<i>19 years a severe M.E. sufferer & absolutely offered nothing in this time, or given ignorant advice. In the West Midlands, where I live no support clinics & very little support from GP's, for a condition that no one can treat. Far too much ignorance & lack of support in the NHS.</i>
177	<i>I got diagnosed with ME at age 8, I live in Scotland and we have no paediatric consultant for ME, CFS or ME/CFS in Scotland.</i>
178	<i>Too ill to attend clinic</i>
179	<i>When I was first diagnosed, my gp at the time told me I didn't have it as was posh people who say that, after 4 years of suffering and finally knowing what I had I was angry and upset, I then sent her all the leaflets that I had, when I saw her again she said that they were very interesting and that she had someone else had someone else to see her who had M E, after that she was very understanding.</i>

180	<i>I first had M.E as a child in 1985. I suffered awfully as my doctor didn't believe there was anything wrong. She told my parents that I had 'school phobia'! 18 months later I had recovered and had 10 healthy years until it suddenly came back. This time I was virtually bedridden for 6 years and lost my career and everything in fact. This time my doctor believed me, but I was horrified to learn that no progress had been made in diagnosis/cause/treatment. From my own symptoms I know that oxygen levels in the body and immunity is a real factor in this.</i>
181	<i>Re. Clinic-I was advised by my gp that the long distance travelling would not be suitable, considering I had two small children, no friends or family near by to help and a partner in London most the week. (My partner has had to work from home 3 days a week because of me)</i>
182	<i>The paediatric consultant recommended the lightening process, which considerable helped my daughter. She is now able to live a normal life and work full time. I feel the NICE guidelines are incorrect for ME/cfs. If you could only walk with a walking stick and had to sleep 16 hours a day, how would trying to go for a walk help. If you had flu would you expect to be told to get out of bed and get on with your life or would you be advised to have bed rest until you feel better!!!perhaps the people who advise this should try and go out for a walk when they feel ill!!!!</i>
183	<i>I have given up on healthcare professionals. I feel abandoned</i>
184	<i>there isn't a clear biologicaly sound, evidence led diagnosis and treatment plan for M.E. . After 16 years fully housebound I hope one day to live free of M.E. again, I am now 40.</i>
185	<i>Very little support in the south west so we have opted for private care</i>
186	<i>Once the diagnosis of 'CFS' was added to my notes, pretty much every GP and consultant I saw automatically assumed I was a hypochondriac. That resulted in serious delays to the correct diagnosis of my condition. Despite the initial diagnosis, I do not have 'CFS' (if only because this label is a 'dustbin' diagnosis that doesn't actually exist in the real world). What I actually have is secondary hypothyroidism, combined with (or possibly linked to) dysfunction of the small intestine as a result of Small Intestine Bacterial Overgrowth (which in turn it would appear is linked to a genetic malformation of my large intestine). I have now successfully achieved a correct diagnosis which is accepted by the NHS (although I had to spend thousands on private specialists to get to that diagnosis) and am receiving appropriate (and largely effective) treatment. But the misdiagnosis of 'CFS' (on the basis of symptoms and routine blood tests alone) has resulted in it taking 13 years to get an accurate diagnosis. It also resulted in me totally losing trust in the medical profession. I am one of the lucky ones... I am educated to PhD level as a scientist and engineer and I had a small pot of money to throw at private specialists. But even then, I lost 13 years of my life along with my original career, and came close to suicide along the way.</i>
187	<i>I felt abandoned after a vague diagnosis by a rheumatologist. My nearest ME. Clinic was too far for me to travel especially considering the nature of the illness. I continued to work which made me worse. It has taken me 8 years to finally feel that I'm managing my symptoms by pacing and limiting activity, but I have had to help myself by researching online and using support groups of other sufferers. I feel there is no help available and we are still misunderstood and abandoned, other conditions such as MS, diabetes, arthritis.. get more research, recognition and help</i>
188	<i>My surgery has no time for patients, let alone discussions about ME. They seem to be happier to just focus on fibromyalgia and throw drugs at me, instead of helping me cope with my illness.</i>
189	<i>pwME are the experts on this illness. Through trial & error & with the help of the Internet we've learned/shared many things to aid recovery. Why are we not being listened to?</i>

190	<p><i>GP was useless. No help. No advice. No care. First GP told me that he believed that exercise was recommended to treat ME! How wrong he was!</i></p>
191	<p><i>I was diagnosed by my pain management specialist, he has looked after me for over ten years due to chronic pain/spinal surgery/nerve damage this is private not NHS. I had no choice I was in so much pain I used to pass out. My Doctors practice was informed via a letter. My GP is lovely but she isn't a specialist, I have never been referred to or seen anyone about my diagnosis. I am broken and I have no support or help and it's wrong and cruel. All the support there is for MS and there is nothing for ME and we suffer just as much if not more.</i></p>
192	<p><i>I fought to see an Immunologist. Waste of time! He diagnosed me with CFS and gave me no solid advice other than 'try not to retreat to bed'...oh and four books I could read about ME/CFS (three of which I told him I had read, albeit with difficulty due to cognitive issues). He told me he couldn't really offer any further advice as he felt I was already adopting the advice that he would usually give (e.g.. pacing, relaxation, etc)</i></p>
193	<p><i>Doctors should be more educated and willing to listen to the plight of ME/CFS patients. It takes too long to obtain a true diagnosis. This condition is devastating to both the sufferer and their family. More help and support is crucial to help cope with not just the debilitating symptoms, but support for the loss of identity, as bit by bit quality of life changes beyond all recognition. The pain and exhaustion are something you never get used to. Knowing that there is no effective medication at present makes it quite frankly, sheer hell to cope and in turn affects mental health too. I sincerely hope that the new NICE guidelines are shaped around the true experiences of people like myself, who finds the much varied symptoms and coping alone, a distressing battle every day.</i></p>
194	<p><i>I was diagnosed at 17 and got physio and CBT along with re-assurance that this is something I can always come back for more help with</i></p>
195	<p><i>I tried for 11 years to see a specialist, there were none. After 15 yrs I found a clinic. Still waiting for an appointment for both.</i></p>
196	<p><i>My GP gave no advice. I saw another GP who confirmed CFS. No advice. I wasn't sure I had CFS. I was also told fibromyalgia. Another health professional rheumatologist f said to start tai chi, an exercise in water class and acupuncture. Tai chi helped, and acupuncture but the water exercise I had to stop as was ill for 3/4 days afterwards. I'm still unsure if I have CFS, 4 years on.</i></p>

197

Yes, the first Dr I saw said he thought I was depressed and when all the blood tests supposedly came back normal, not knowing what was wrong with me then, I was made to feel like there was nothing wrong! The receptionist said, oh all tests are normal, goodbye. I still felt incredibly ill, but had no where to turn, but luckily, soon after, I came across an M.E leaflet just before I had to give up my job. This was all within four weeks of starting a new job.

Many years later, I was offered a place at Southamptons clinic, but from just looking at there questionnaire, it was based on a depression scale, not physical symptoms. My carer established it was group based talking therapy, none of which I needed and was far too ill to meet in a group session. I needed help to manage deteriorating heart problems, education for sceptical Drs, practical help.

I was told by my then GP I had cardiac Insufficiency and this was on the same day my mum was told her heart was failing. My dear mum died within just a few weeks. By the time I went back to my GP, she had a cardiologist, (supposedly looking to venture into general practice) at the session and then told me, Oh, I told you that you had cardiac Insufficiency to appease you!! The cardiologist piped in and said, oh there's nothing wrong with your heart, this was all done without any physical examination. I was stunned, as was my carer. On the way out, I suffered a massive angina attack, so the carer went back into the GP's office and she then agreed to a cardiologist appointment.

The cardiologist appointment was a total farce. She said I had microvascular angina and would contact my GP to start me on meds (that never happened, as it wasn't even recorded in her letter to my GP and she denied saying it, even though I was again accompanied by another carer). My attacks of pericarditis (in excess of 25 attacks at that point), were put down to a bit of pericarditis. The later heart scan revealed a lot of epicardial scarring, so not just a bit of pericarditis, but no follow up appointment... My intermittent racing/jumping arrhythmia was put down to ectopic heart beats and even when I had massive attacks of this, accompanied by severe angina pain (when I thought I was going to die), I was laughed at and not taken seriously. I was also told to take off my dark glasses, as she couldn't see my eyes! My tachycardia (136 beats per minute) and angina was ignored when she asked me to get on the examination table. This was after she had just told me that people like me are just more aware of there heartbeats. However, I wasn't aware that my hear rate had shot up to 136 beats per minute, so that shot her theory down instantly.

I could go on. Abuse after abuse by neurologists, GP's, autonomic specialist, even the lady serving breakfasts at the London autonomic hospital - she said, oh, all you need is positivity; you should be grateful that you can talk, people in the next ward couldn't but wanted to. Considering I had just come out of being very severely ill and not being able to talk for months, her ignorance was very hurtful. Now, this was astounding and she was never reprimanded, as the consultant put it down to me misinterpreting her... ahhhh, no.... He was just as scathing. Ignoring UTTT results of tachycardia, even though I had syncope... My M.E went back to being very severe after this brief spell in hospital for tests. What they didn't seem to understand was that had I been offered a place at the time my GP first referred me, I wouldn't have been able to go, as I was too severely ill, couldn't talk, only whisper, wouldn't have been able to tolerate the tests. As it was, they showed no understanding of severe M.E and put me on a ward, albeit a small one, but couldn't see the connection between, light, noise and me being really ill...

Something good has got to come out of this consultation and NICE should not continue with any clinic, GP, consultant offering graded exercise and therapy. It is wrong on so many levels...If someone with M.E requests counselling and help, it should not be based on the premise that the person isn't really ill and they can be cured by cognitive behavioural therapy, what utter tosh. Therapy should be based on helping the person with M.E cope with massive changes and equip them with coping skills, practical occupational therapy help (how to conserve energy), and a list of consultants with expertise in M.E.

Thank you.

198	<i>I am also diagnosed with fibromyalgia</i>
199	<i>I attended a clinic in Montreal and it took 6 years to get my diagnostic.</i>
200	<i>A Neurologist offered me physio. This helped reduce pain/stiffness. Her advice to reduce daily activity also helped. It was helpful that I had a neuro specialist physio who treated me the same as she did her MS patients (she treated me as she would any other biological disease patient). The Neurologist did refer me to general psychology where they offered CBT, psychotherapy or ACT. I chose psychotherapy but it never came through on the NHS (4.5 years and waiting...). I then had counselling at my workplace and that helped with coping with the illness, but had no impact on symptoms. Basically, these services helped with symptom management and pacing which led to a very mild improvement in my symptoms and coping, but in no way have improved my ability to work beyond part-time or got anywhere near resolving this illness.</i>
201	<i>I was diagnosed 30 years ago</i>
202	<i>I am 49 and live in Ireland. I have severe ME/CFS. Housebound with severe gastroparesis. I have a gastric pacemaker and gut failure, requiring jejunostomy feeds and likely to need TPN soon. I vomit 8-12 times every day for past 33 months. Ireland has NO ME/CFS Consultant/specialist centre/services. I am not eligible to attend ME/CFS service in the UK. No one is caring for my ME/CFS. My GP is compassionate but does not manage my symptoms. My gastroenterologist only manages my gut issues and does not take into account the full autonomic nervous system dysfunction with ME/CFS. Irish Drs, healthcare employees, policy makers etc rely on NHS/NICE to guide practice. Please consider the NHS/NICE impact on Irish sufferers. Thank you</i>
203	<i>Awaiting appointment at local ME/CFS clinic with no idea of waiting list or how to chase this up.</i>
204	<i>very little support from any professional, told was in my head</i>
205	<i>I live on the Isle of Wight. In 2010 a Lifestyle Management course was run for a group of approx 10 people. Nurses came over from Southampton to do this!</i>
206	<i>I receive no help and have to figure it out on my own.</i>
207	<i>I have been ill with ME for 17 years and during all this time there has never been an ME Clinic/specialist in my geographical area and funding has been requested but not forthcoming from my local area to access these services. I have been left to rot.</i>
208	<i>I received no advice about improving/managing M.E. (I was diagnosed in 1986, so I appreciate that this was a long time ago, but no medical person has since given me any advice either). It's only relatively recently that I found out - through information on a M.E. forum - that I should be pacing & resting rather than 'pushing through'. When I look back at the times I pushed myself way beyond the boundaries (carrying on when I could barely walk, breathe, talk ...) thinking that I was 'fighting' (I wasn't going to be beaten) it makes me so sad. I think for sure - that I could be not as ill as I am now, if only I had received information to be careful, to rest, that pushing was not a good thing - but rather was very harmful. Since finding out about pacing, I have 'managed' the illness a little better - & have limited the severity of the crashes - but I am still very ill now - & wish so much that I had been given appropriate advice sooner.</i>

209	<i>I was diagnosed in 2011. I have very gradually improved over these years. I believe that listening to my body, resting and pacing have helped me to get better. gentle exercise such as chi gong and yoga were helpful. I now rarely have post exertional malaise but it does happen maybe once or twice a year if I overdo. I also believe that meditation (especially yoga nidra) and self compassion played a large role in my recovery. There were no specialist services in my area when I was diagnosed. However, I knew a lot about pacing, having worked as a psychologist in a chronic pain service. If I did not know about this I might still be ill. I hope this info is helpful. Thank you!</i>
210	<i>My consultant is [a professional] now only available privately. Local NHS closed ME service.</i>
211	<i>I have participated in post exertion malaise studies at The University of Wisconsin Madison, directed by [a professional]. I was one of the few patients who had recovered enough to complete the exercise portion. I did help prove the theory that exercise and mental activities trigger symptom flare ups.</i>
212	<i>I have never been offered to attend an ME clinic, I received my diagnosis in 2006, following a couple of years of being unwell. I've been mostly housebound for 11 years & bedbound for 3. I have no regular medical support, I am 2 years overdue my cervical smear, as they won't do it in my home, however I am one of the lucky few who's doctor will do home visits if I need. My GP's aren't very supportive/knowledgeable of the ME.</i>
213	<i>I was initially sent to St Thomas' hospital in London to see a Professor who claimed to have 'cured' ME within a year with anti-depressants. He insisted I take a cocktail of anti-depressants against my expressed wish not to take them as I was not depressed, I was exhausted! I became much worse when taking them: difficulty breathing, insomnia sometimes lasting up to 4 days and nights, rapid weight gain which I have not been able to lose. These symptoms stopped when I stopped the pills of my own volition. I did not receive any other support or medication. I was ignored by my GP so I stopped going. I used alternative medicine i.e. acupuncture, homeopathy, herbal medicine and supplements to keep myself functioning. It is now more than 25 years and although I continue to suffer various symptoms, particularly brain fog and fatigue, I am able to function. This illness is caused by a MUTATED Epstein Barr virus which research will one day discover. Until then the usual allopathic process is followed, i.e. treating individual symptoms rather than the cause, but marginally better than denying the existence of what for some people has been a deadly disease.</i>
214	<i>There isn't a clinic in my area.</i>
215	<p><i>A great deal was once known about myalgic encephalomyelitis (formerly called atypical polio) and Dr Melvin Ramsay's criteria best describe wide-ranging symptoms of this devastating neurological disease. Unfortunately, the decision to change the criteria in the late 1980s and rename the disease as chronic fatigue syndrome has led to the loss of important knowledge and to the unnecessary suffering of countless patients. As evidenced by the current NICE guidelines, ME is erroneously seen as a psychiatric condition.</i></p> <p><i>A diagnosis of CFS was originally intended as a starting point for further investigations. Instead, it has become a meaningless non-diagnosis that has created a medical 'under class', a group of patients who are left to languish in a state of profound physical illness for years, even decades, without treatment or care. Worse still, even though the World Health Organisation has, since 1969 recognised ME as a neurological condition, many people are given dangerous advice to undertake graded exercise which has led to permanent, often severe, neurological damage and even death. This mis-advice is like telling someone with Parkinson's disease or MS (comparable illnesses to ME) to exercise.</i></p> <p><i>We urgently need investment for bio-medical research to further current findings about mitochondrial and brain malfunction and the systemic impairments they cause) and we need safe, effective</i></p>

	<i>treatments. I implore NICE to provide accurate information regarding diagnosis and treatments to reflect the nature and gravity of the condition and prevent further medical casualties. Many thanks</i>
216	<i>I saw a private specialist because part of my illness did not enable me to attend a clinic or similar where other people will be present who may be wearing perfume, strong washing powders, etc. My CFS is related to MCS.</i>
217	<i>No</i>
218	<i>There was no help or knowledge about the problem.</i>
219	<i>In 21 years since Diagnosis I have only been offered Prozac on the N.H.S. Other treatments and alternative treatments I have paid for privately.</i>
220	<i>My rheumatologist diagnosed me with fibromyalgia and not CFS because he said you can't have both! I was diagnosed privately 3 years later and not by the NHS. Subsequently, despite a re referral to the the rheumatologist by my GP this year he still wouldn't allow me access to an ME clinic because he personally doesn't believe you can have both diagnoses! Due to not having an early ME diagnosis I believe I have lost my chance of recovery.</i>
221	<i>NHS drs have always been clear there is nothing they can offer to help with M.E. and are directed by me when it comes to caring for that condition. As one private specialist I consulted with said "they expect me to project manage my own illness" which is a ridiculous burden to have on top of suffering from something like M.E.. This has been the case since my diagnosis in 2005.</i>
222	<i>My GP failed to inform me for 10 years until a consultant told me. I was supposed to be referred to an ME clinic but it had closed down in between</i>
223	<i>The last time I went to see my GP to discuss the possibility of receiving magnesium injections to help with my symptoms I was given the PACE trial /NICE guidelines of CBT/GET which I know were not only a product of poor science and DWP funding, but is completely inappropriate at best and catastrophic at worst. Ever since this appointment 2 years ago I have completely given up what was already very rare appointments to my GP in the hope of help. I do not trust doctors to help with my ME, particularly with the current NICE guidelines in place.</i>
224	<i>I have not been officially diagnosed despite requesting this I have just been told it's very likely I have ME/CFS. I was referred to the centre for integrative care in Glasgow after having to request for it specially and was offered homeopathy and a physio who suggested graduated exercise therapy which I tried but it made me much worse. I am now not receiving any supervision or treatment but am unable to work full time because of my CFS/ME and it has a severe impact on my life. I wish my doctor had more information about CFS/ME and that there were other supports available for living with the condition.</i>
225	<i>Initially I should have decreased activity levels (I was working too hard following an infection). Then it really helped to very slowly bring back routine into my life (so gradually increasing activity). Now after 10 years, I feel much better</i>

226	<p><i>I was diagnosed with ME/CFS in the UK after several years of my doctor believing that my issues were anxiety/depression related. I think I was only then diagnosed following a private consultation with Dr. Sarah Myhill in Wales.</i></p> <p><i>I subsequently moved to Vancouver Canada where I was referred to the Complex Chronic Diseases Program at the BC Women's hospital. Their approach is primarily on symptom management as they stated very clearly that no treatment would be offered unless it was well researched first. They offer no GET and instead, focus on encouraging patients to pace themselves. As you are looking at NICE guidelines, you would do well to contact them. They apparently have a group of people who look into the latest research. Dr. Arseneau developed the program.</i></p>
227	<p><i>I became ill as a child and have been ill for forty years. My symptoms deteriorated steadily throughout my childhood and early adulthood as increasing pressure was put on me to maintain activities, which I attempted to do. I am now severe/very severe, bedbound and cared for by my 74-year-old mother. She loses sleep worrying about how to pay for care for me in the future. If we had been given sensible, kind advice early in my illness - to rest as required - it is possible that I would now have some quality of life and independence as an adult. What has happened to us is a disgrace. My life has been stolen and destroyed by bad medical advice.</i></p>
228	<p><i>A locum GP referred me to the hospital in Liverpool who diagnosed me. I was then sent to another hospital in Liverpool to attend a few hours with other ME sufferers. Not much advice given, lots of sufferers talking about their own experiences. No other help received from GP no referral to ME. Self care is necessary and support of family (I am extremely lucky with my family) .</i></p>
229	<p><i>Received good care and advice from a cranial osteopath and homeopath, as well as from GP, who wisely recommended a lot of rest. // Condition much improved after 3 years of rest, healing diet (to heal permeable gut), B12 in methylated liquid form, etc. EBV kept recurring; once this was tackled, recovery was stronger. // Did not use NHS CFS services, because they do not seem to look at the whole patient. The graded exercise currently recommended by NICE is positively dangerous for much of the illness; it is only suitable in later phases of recovery. This is another reason that we avoided NHS CFS services. // Dr Myhill's website on CFS was very useful for learning about the different elements of the illness and tackling them. // When the NICE guidelines are revised, please look at the whole patient. Take account of the many different elements in CFS; including recurring viruses and possible thyroid issues. Please give better advice re. rest (more of it) and do not promote graded exercise, until the person is well on the road to recovery. //</i></p>
230	<p><i>I want to type more but I am too ill.</i></p>

231

When I was diagnosed in 2007 specialist ME clinics did not exist. Luckily my father had private health care insurance for me so I was able to see a specialist quite quickly. I was first referred to a consultant gastroenterologist. After various tests and scans he told me I had post viral fatigue syndrome. I felt very confused because what I was feeling was much more than tired, I was struggling to walk and dress myself. He said that would go away within six months. In the meantime he referred me to a consultant psychiatrist who specialised in chronic fatigue syndrome. Unknown to me at the time my health insurance had refused to pay for any of my treatment because ME/CFS is not a real illness! My father had to cover all my medical bills himself.

The consultant psychiatrist I saw told me that my brain was confused and was telling me I was tired when I was not. The way to fix this was graded exercise. Not only was I to walk multiple times a day but I was not even allowed to lie down to rest. If I wanted to rest I had to do it in a sitting position. I found this incredibly difficult because at this point in my illness I was in bed or lying on the sofa most of the time and sleeping frequently. In hindsight I think pushing my body when it was this weak delayed my recovery.

Over several years I did see some improvement and was able to begin living semi normally. What this due to graded exercise? I am unsure. I think had I been able to increase my activity level in line with what I felt my body was capable of I probably would've improved much quicker. I walked daily as recommended by the doctor but then would be so exhausted for the rest of the day I could do nothing else. I believe this hampered my recovery rather than helped. I think ultimately my body was recovering by itself and would've done so whether I was using graded exercise or not.

Six years after I originally got ill I suffered a major relapse. I went from being able to work and live by myself to needing full-time support from my parents. Implementing grade exercise after this relapse made absolutely no difference. If anything it seemed to make my health worse.

The consultant psychiatrist I saw, [redacted], I believe went on to set up CFS clinics several years after I had stopped treatment with him. I can only assume the clinics provided the same treatment he gave me.

At present doctors treat ME/CFS as a psychological illness but that is wrong. It is a physical illness with a physical root cause which needs research My ME was triggered by kidney infection. After a month of antibiotics the infection had gone but I remained weak and exhausted. To be told the reason for this exhaustion was because my brain was confused is quite frankly insulting. There was no reason behind this and no logical explanation given to me as to why this had happened. At the time I was too ill to query this and was just desperate to try anything to help me improve. When it comes to treating ME/CFS I have very little faith in mainstream doctors. One GP I saw was very dismissive and basically told me it was all in my head. Others have been understanding but they are still unable to offer me any solutions. The NHS really needs to educate its healthcare providers on this illness.

I have explored many other treatment options. Below is a list of things I have found improved my condition.

CoQ10

Magnesium

CBD oil

Acupuncture

High doses of vitamin C to support the adrenal glands

MRD diet developed by Dr Alan Christanson to improve liver function and help with hormonal balance

Atrantil a herbal antibiotic used to cure SIBO

Functional medicine has provided me with many more answers, solutions and improvements than any mainstream doctor has. I really wish the NHS would adopt this style of treatment

232	<i>I have never been offered any services to help, just left to get on with it!</i>
233	<i>I have had this for 28 years with fibromyalgia too. There were no clinics in the early days and by the time one was set up near to where I lived (an hour's drive) I had had this for 17 years. There was nothing they could tell me that I didn't know already. I was left to manage the best I could with pacing and resting when pain built up or legs gave up. Tried everything as you can imagine to get better but no medication helped with pain always side effects. I was one of the lucky ones not to be bedbound but have had spells of being housebound because of pain in legs and back and an increase of fatigue. Affected every day but I have to pace it and take short rests if pain builds up and fatigue.</i>
234	<i>Took over 5 yrs to get a diagnosis back in 2000 (differing since 1995/1996) was told many times there was nothing wrong with me or I was depressed which I am not and can honestly say nothing has improved from medical approach - very dismissive - my rock has been Dr Raymond Perrin osteopath who honestly been the only person who ever made any sense of my symptoms and given physical and practical advise !!! Time for medicine to catch up to the realities of autoimmune / dysautonomia / neuro inflammation and stop dismissing millions of people who are all saying the same thing - we are not depressed !!'</i>
235	<i>Was not aware of any clinics or specialised support - I have to mention it but no reaction or help offered. Diagnosed 16/17 yrs ago</i>
236	<i>I have received utterly appalling service from my GP practice who have provided minimal testing. They are of the belief that thinking positively is the solution. I have worked out the cause - a biofilm protected bacterial infection which causes Increased Digestive Permeability which in turn promotes inflammatory processes which affect ATP production and immune function. Coupled with this I was bitten by an insect on the back of the head when I fell over while attempting to peg out washing in the overgrown garden. The insect was embedded in my head. This has caused significantly more exhaustion, to a hitherto unexperienced level which I used to successfully managed for 25 years with a none changing diet to eliminate the immune system reaction to food. My GP has refused to perform a Lyme test claiming that there was no bulls eye rash (possibly the result of immune dysfunction) and claimed that ticks are not present in gardens despite other insects being capable of spreading the lyme bacteria. Besides the insect was embedded in my head which seems a lot like a tick's behaviour. The same GP works at all local GP practices therefore changing GP practice would make no difference. If I can possibly find some energy and wake time I hope to submit a complaint about my GP.</i>
237	<i>There is still a lack of support within the GP practice and NHS</i>

238	<p><i>I had the most excellent G.P. (sadly she has now left so unsure of others' attitudes/advice within the GP Medical Centre). Kept record of notes of consultation. Some years ago there was, however, (thankfully now retired!) a terrible G.P. who said to me (this was on advice of caring employer requesting I get signed off at least 2 weeks) 'oh NO, you must CARRY ON!' APPALLING! From then on I refused to see him for anything! However, last excellent G.P. was absolutely wonderful; even explained/reassured me abt. some post-viral symptoms I can still get, some swelling of joints, even in hands, which not used during particular exercise. This wonderful G.P. I felt 'knew my body' better than I did! Emphasised I must 'PACE' which I do. She did offer me C.B.T. to 'help cope with it' but being a somewhat 'feisty' individual, I said 'thank you but No; if anyone else has a problem with this, it's theirs, not mine' ! 'You sound angry'. she said, which I do ; this was also case with a friend of mine with what I call 'full-blown' M.E. - I suggested she stay away from 1 'so-called friend' who had made an unkind comment to me about her - which we both did. I manage zumba, other dance classes but can NOT do a whole day workshop or whole weekend event. Get tired of explaining to others who are 'up for it' - just say I'm 'busy'....No time whatsoever for anyone who gives me a 'hard time'/can't be bothered to understand including 1 or 2 family members so I remain rather more distant from them. I am 'in control' more of who I 'mix' with, communicate with.....and am OK with it! Accepted it a long time ago. I do very much, indeed, appreciate what I CAN/am able to do & feel terribly sorry for anyone suffering far worse than I do. I did, finally, persuade a friend in the village to go to G.P. & get a DIAGNOSIS, which she eventually did!</i></p>
239	<p><i>I have had CFS/ME for over six years now and have still had no support with it. There is no service in my area and the area I used to live in they wouldn't take me. In a way I am grateful as I would have just been offered GET. But at the same time I was out of education and work for three years and housebound for much of this, and the lack of care is unacceptable. Everything that has improved my condition I have had to work out myself the hard way, and I had to fight for every referral for my concurring conditions. Even then there has been so much stigma, misinformation and lack of understanding from professionals about ME/CFs and what it does to people.</i></p>
240	<p><i>There are no M.E. specialists or clinics in Scotland.</i></p>
241	<p><i>We need doctors & all health professionals to be educated & for it to be part of their training, secondly, making an advert on the TV to show the general public the real side to M.E. would help a better understanding & quash some myths that people hold towards this illness.</i></p>
242	<p><i>Offered appointment at [a professional's] clinic. (2000) . Was bedridden so unable to attend. The hospital Registrar phoned from London to say no facilities for bedbound patients anyway. She said to look at their website for instructions.</i></p> <p><i>GPs had no understanding of the illness, especially in its severe form.</i></p> <p><i>When in hospital in 2012 consultant read information we took in about ME and he said 'why have I never heard of this?'</i></p> <p><i>2018 died aged 40 - ME on death certificate. 18 years bedridden the last six of which were hell on earth</i></p>
243	<p><i>I was diagnosed and given a page printed from the NHS site which described symptoms etc. No discussion of treatment for symptoms I was experiencing, no mention of clinics/support. Just this is what you've got, there's nothing we can do. I've muddled through on my own since the age of 8 when I first developed symptoms and 23 when I got a diagnosis. And they wonder why ME sufferers seem to have higher instances of depression.</i></p>
244	<p><i>My own(sometimes expensive) research has somewhat helped symptoms a bit.</i></p>

245	<i>I have been waiting over 18 months to see someone to help me manage my symptoms and pace myself however I have found some great advice from others suffering g as myself and got some tips on how to pace myself. If it wasn't for this help and advice from other sufferer's I dobt know how I would have got through the last 18 months.</i>
246	<i>I have yet to find any actual help or advice from GPs and feel alone with my condition. I was diagnosed through my husbands medical care and then referred back to my GP. I have told then that I have had ro stop working but I don't get any response. It very much feels like it depends on who you speak to rather then a standard need for care to so with the condition.</i>
247	<i>There are some doctors that understand ME/CFS and others that do not. There are some treatments that improve symptoms, however there is no magic spell currently. Doxycycline, ldn, rehydration vitamins etc can help, but it is extremely difficult to hold down a job. Chiropractic techniques can help on a temporary basis for pain and brain fog. I personally get offended when doctors start asking psychological questions. We are missing a national database of patients and the treatments that are most effective. We are also missing support frameworks to assist with this debilitating illness. I have been lucky that I am able to work from home... my employer has been very understanding as I did 10 incredible years at the firm. At some point their good grace will run out. At that point I do not know how I will support my family.</i>
248	<i>Better guidelines for doctors to understand. When been taken in to A&E medical professionals have rolled their eyes and looked at me saying am nuts. My GP is fab though. The clinical psychologist who diagnosed me said there needs to be more leaflets that explains that ME/CFS is different for everyone with various different symptoms. Another suggestion is links to support groups through Facebook. It helps me with talking about it to others. More groups that can be accessed easier. Better support for GPs to help support the patient when ME/CFS flare's / relapse. I feel like a failure sometimes when I relapse really badly. Suggestion would be alternative therapies</i>
249	<i>Not enough help and doctors don't have proper understanding to help suffers</i>
250	<i>There is a service but neuro refused to send me to it as also labeled functional disorder so sending to local rehab for brain injury. All psych and excercise based</i>
251	<i>That a lot of sufferers aren't offered any follow up after diagnosis and we should be.</i>
252	<i>Doctors or Speciliasts knowing truly understanding the condition and how this has an impact on the sufferer.</i>

253	<i>My symptoms started around 1997 and all my GP could offer were vitamins and he kept saying he didn't think I had ME. Finally after pushing for a referral I was referred to Monklands hospital in 2003 and diagnosed with ME after many tests. This diagnosis was backed by Glasgow Royal Infirmary in 2004. I had now deteriorated during this time. If GPs were more aware then I may not be where I am today, almost housebound with no benefits, can't work, can't be a blood donor or organ donor. My husband has to support me and that has an effect on my mental health. I have been given no help or advice even though I ask. I have now given up asking and do my own research as no one is interested and it's hard enough getting people in the medical profession to understand what ME is. The only advice I was given was graded exercise at Monklands Hospital many years ago. I had to give up half way through the programme as I was now worse than before I started. I haven't worked since 2003 and do not think I will ever be able to commit to work or even volunteering as my condition is so unpredictable. Some days I can't wash or dress! We are the forgotten people. Out of sight, out of mind. No one cares. How depressing. No wonder people are depressed on top of ME. No light at the end of the tunnel. A slow death. A living death. Help us get a life back rather than half lived.</i>
254	<i>It took 6 years to get diagnosed and that's only because I found out myself then asking the doctor if it was ME. He said he didn't like the term ME he prefers CFS. I don't care what they call it I just wish the doctors had believed me when I was so ill. Doctor has said there's no cure.</i>
255	<i>I was bedbound for many years and found there was no help for the severely effected</i>
256	<i>I have never been offered access to a specialist me/cfs clinic. I have been told there are none available in my area. Instead I have been offered CBT and access to mental health services.</i>
257	<i>I was given a diagnosis in 2017 after years of my symptoms being blamed on depression. One test result (which was later found to be misleading) meant I was discharged without being treated (Sutton). I was then taken into hospital having deteriorated to being in a wheelchair for tests. The diagnosis I had and Functional Neurological Disorder was ruled out by some consultants (Kings College Hospital). I was given a discharge note to go to the chronic fatigue service at a different hospital in March. The paperwork said it wasn't FND. I was invited to be seen by the FND team at the Bethlam Hospital as I was declined funding. FND team went back to the SAME consultant to confirm three months later that it still wasn't FND. No one was informed that I was declined funding and needed to reapply until I rang up the hospital for information (The Maudsley). My GP referred me again and this September I have been informed that I have been given funding for GET. No choice in options and I haven't been seen by anyone at the CFS clinic. I feel like I could have been treated in 2017, would still have my mobility and have been messed around by bureaucracy. I could have been referred in March, yet it took until September to get on the waiting list. Why is it so difficult?</i>
258	<i>more doctors should know how to diagnose and help those with ME/CFS, you shouldn't have to go to see a specialist (that may cost extra) for a diagnosis since some with ME/CFS don't work/ have income. i had an okay experience but it took a lot more money than i expected.</i>
259	<i>Doctors think I have a "mystery illness" and that's it</i>
260	<i>At no time was I advised on attending an ZME/CFS clinic. My daughter has same as me and she attended one but did not find any of it useful. Which is why I never pursued going to one.</i>
261	<i>More awareness and more help on this would be great. As I feel most people are left to deal with it themselves, and manage it.</i>
262	<i>When I was first diagnosed, I was bedridden. By following the advice to rest when I felt ill enabled me to gradually improve over the next 5 years. My remission lasted 16 years until the menopause and stress caused a relapse which has lasted 10 years. My abilities are at 25% of my life before I had the virus which led to ME.</i>

263	<i>I have not attended a clinic or specialist ME service because there isnt one. In almost 20 years I have had no specialised help or support from NHS. I cannot imagine there is another illness that is so life limiting that gets such little care.</i>
264	<i>I didn't know there were services available in my area until looking at this survey. Beyond CBT and Physiotherapy, I have never been offered or suggested any other kind of help. Having been through multiple stages of assessment; GP, consultants, physiotherapists, psychologists - I would have thought that if there was a specific service for people like me they would have talked to me about it. Especially since I'm a student, which means anything that causes a set back hugely impacts the qualifications I will receive. I've had CFS for coming up to 5 years now, and no one has ever suggested that there is a service designed to help people like me.</i>
265	<i>I feel I was fobbed off by doctors as they didn't know much about it</i>
266	<i>I think GPs use CFS as a label other than exploring everything. The best advice i have sought is from my own research and trying different things, endless appointments to private advice at my expense and just being left to cope with my condition the best i could. I think the advice and support could be better. I have gotten better from being persistent and stubborn.</i>
267	<i>I became ill in 1993 age 35 following severe influenza, the modern clinics did not exist. I returned to work after a couple of weeks but continued feeling very ill - felt very like when I had hepatitis A - with severe nausea so became very underweight. I forced myself to keep going but was never able to return to the very active hobbies and social life I had right up till the onset of the flu. My gp found nothing wrong, after several weeks said Post Viral Syndrome. As the months passed and I did not improve, continuing to force myself to the maximum to keep going. I had always loved exercise, dance, the outdoors, yoga, and believed I could cure myself - but was gradually deteriorating. My GP referred me to a rheumatologist, who said I was a "heartsink" patient. I was then referred to a psychiatrist, about six months in, who said I was adopting avoidance behaviour (what I was avoiding? all the activities and life I loved?) diagnosed "neurasthenia" and told me to exercise more (without asking about my history or extremely active lifestyle right up to onset), prescribed antidepressants (fluoxetine). I took the antidepressants as instructed, felt increasingly worse, on the follow up he told me to increase the dose. He never looked me or my husband in the eyes. I continued absolutely forcing myself to keep going when feeling dreadfully ill, feeling even more I had to prove I was not avoiding anything, getting worse and worse. After 15 months I was housebound and partially bedridden, had to force myself to eat tiny amounts from the severe nausea and could barely lift a fork, or talk. My husband met someone who knew about ME, and he was sure I had the symptoms. My husband (who is a doctor of psychology) had also noticed the delayed effects of exertion which I hadn't. I didn't want to believe I had such an illness. They told us about an ME consultant at NHS Preston Royal [redacted], long waiting list. Over two and half years from onset, I got to that specialist. I had to be taken with wheelchair, and during the wait had to lie on the floor in the waiting room. The consultant, [redacted], said that was not unusual with ME patients. Thorough tests and assessment gave a definite diagnosis of ME. I finally had advice to pace and manage the condition correctly, but a lot of damage had been done by then. [The professional] retired soon after and his clinic was closed, there was no other provision on the NHS at the time. I have never been able to improve beyond "virtually housebound" at best, hence unable to undertake a course such as provided in current CFS clinics. However I have had instruction and practised CBT and mindfulness and always tried to be as active as possible - I find it hard not to overdo, howsoever little it may seem. In addition to the physical damage, I've suffered emotionally and psychologically from the attitudes Ive met with over the years -and which are still prevalent in the medical establishment, and in the media and so in general society. I'm sorry for writing so much, but so many of us have become long term severe as a result of those attitudes, and the refusal to accept biomedical research around the world. I beg you to listen to patients experience, consider ALL the scientific research, and allow ME/CFS patients the respect and condition-appropriate care given to other patient groups.</i>

268	<i>Funding is a major issue preventing my child from getting support for the Yorkshire fatigue clinic.</i>
269	<i>I've attended a Pain Management programme at Northern General Hospital which helped me manage some of my health issues as I also have chronic pain. The Pain Clinic also support patients with ME/CFS within the programme as some of their strategies apply.</i>
270	<i>No testing for things that can cause ME/CFS. After 3 years diagnosed with EDS and a further 3 years later diagnosed with CCI.</i>
271	<i>Had M.E for 42yrs now. Never got any help from doctors. Was misdiagnosed for 19yrs and put in a mental health ward twice and given antidepressants which made me more sleepy. Suffer alot of pain now been house bound and bed bound over the yrs. I live in Scotland and there's no doctors to help us with M.E</i>
272	<i>I would like to add that I admire what you are doing, but also, after everything that I suffered during the years of illness, I have my own opinion on this matter. I realized that if we truly want to recover, then we need to hope first of all for ourselves, and not at all for official medicine. Western medicine can only recognize the disease, but it most likely will not find the magic pill. We must take responsibility for our health, and not shift it to the attending physician. I think we need to turn to alternative sources, study how nature and our body function, and then we will find a solution. After all, our goal is to be healthy and happy, right?</i>
273	<i>no clinics or further advice where i live..</i>
274	<i>It took over 15 years for my gp to even consider Cfs.Was referred to see a nurse to discuss symptoms and was only seen once as finding was stopped.No follow up.</i>
275	<i>Not offered a cfs/me clinic as none available in the area .</i>
276	<i>There are no clinics or specialists in Wales and I am currently 'discussing' with my GP the possibility of being referred outside Wales but this suggestion has not been welcomed and i am being referred back to a local General Health clinic - the clinic where my CFS was originally diagnosed and where I was told that there was no more that they could do for me!</i>
277	<i>I was referred to a clinic but got a letter saying that I was above the cut off age of 65, I was 73 at the time. Recently I was also hassled into attending my doctors surgery to get a blood test when I said that I felt too unwell and have felt much worse since going. They are now trying to make me attend for a BP monitor to be fitted one day and taken off the next as they say it can't be done at home.</i>
278	<i>Very little help in Northamptonshire</i>
279	<i>Not enough healthcare professionals accept that M.E. is genuine or serious</i>
280	<i>I was dx in 1988. There is LESS care in Scotland now than there was then.</i>
281	<i>There are no me/cfs services in my area therefore to far to trvel to nearest. Doctors need more education</i>
282	<i>Responses on behalf of patient with severe ME, bedridden for >7 years. GET ruined our life's .</i>
283	<i>Because I refused graded exercise therapy I was deemed psychologically inept and transferred to a psychologist to deal with my symptoms. My psychologist has taught me how to pace. This should not be!</i>

284	<i>I am in North Lanarkshire and despite several requests my GP advised every year for 15 years that there are no speciality medical professionals or services for ME or Fibromyalgia they can refer me to. I feel completely isolated and unsupported.</i>
285	<i>The survey jumps from 3 to 11,so isn't working. Also how can you grade the advice given if no advice was received? Useless survey.</i>
286	<i>this does not encompass patients who have combined diagnosis of CFS/ME and things that do get better with exercise, or other comorbidities</i>
287	<i>The clinic for my region would have been more than two hours away and illness meant I was unable to handle travel that far and back.</i>
288	<i>Since diagnosis in 2001 I have never been offered any further treatment, medical or physical. I have been left to get on with it and suffer in silence. The only support I have had is from informal ME association groups and online forums/support groups. Given the number of people with this condition would it not be advisory to keep in contact with them (with permission) to inform of new strategies/medications to help?</i>
289	<i>GPs mostly just want to prescribe pain medication. I have been waiting months for the pain clinic in which I'll probably just be offered CBT.</i>
290	<i>My son's symptoms have slowly improved since I have taken control of his health and education and allowed him to pace himself, resting as and when he needs to. Being pushed to do more by an over enthusiastic physio and told to attend school whatever the cost to his health has been an absolute affront to what is common sense. Where is the medical research? Where are the experts? Nowhere!!! What an eye opener it is to enter the barbaric world of cfs.</i>
291	<i>I would welcome an ME/CFS service, alas nothing has been offered. I feel abandoned to this diagnosis with no support in order to aid me in going forward. Instead, along with feeling desperately ill, I am forced to attempt to prove this fact time and time again to individuals and organisations whom have little to no understanding or empathy. It is no longer a life</i>
292	<i>I had a one-off appointment with a specialist nurse (the only such nurse in Scotland). Because I was out of their NHS area I was not allowed to return. Over many years I have tried to follow advice to gradually increase activity, and I have therefore often had bad relapses. I have also had times of listening to my body and resting, and my experience of that is that my energy levels do begin to improve gradually. Twenty years since first becoming ill I fear I will never get back to being the physically fit person I was, though I have improved gradually (by resting and learning to pace). What would make this cruel loss a little easier to bear would be having supportive and understanding medics who can guide effectively or at least commiserate empathically. GPs have to follow NICE guidelines and the guidelines are unhelpful at best and seriously damaging at worst. It has been painful to attend GP services and to hear my experiences described as, for example, "a bit of chronic fatigue", when that has described times when I have had to rest between hanging single items of washing, or had to stop halfway up a single flight of stairs to rest. I was a high-achieving and physically fit person; I would like to be understood and supported as I try to find my way with an illness that has made me feel like a very elderly/infirm person since I was in my early 30s. If NICE can offer good guidelines then it may become easier for me to gain understanding at work and other areas of my life and therefore to be supported in staying as active as I can.</i>

293	<p>Yes i was extremely severe when it started nearly ten years ago. Barely able to hold my own head up most of the time. I was met with a neurologist that did not want to consult, just bark a few things at me. As mine started following an injury, followed a week later by a bad seizure. I had never had a seizure before. I was met with little to no help, even my own GP said cruel things like if i won the lottery tomorrow, i would be fine. I was diagnosed by both the GP and neurologist within a year of being ill, but was not told. My GP told me he suspected it, then confirmed it a few times. But i was far too ill to be sent anywhere, i will give him credit though he knew enough not to put me through GET and suggested pacing instead. My reason for writing this is now many years later, i have also been diagnosed with other things, i am also still trying to find diagnosis, pots and vestibular migraines. Do you have any idea what it is like to suffer severely with these and no one listens, or does the right tests. But this year i have lost my pip benefits, which has taken a massive toll on my mental health. Why you are probably wondering. Well it is not because i am suddenly better and not ill enough, because nothing has changed. Well it is because now i have a lack of medical evidence, because no one did anything for me all them years ago. I was only given medications that severely affected me, have left with me with probably life long stomach and bowel problems.</p> <p>The doctors, the dwp, the tribunal courts, and the health care professionals of this country, have a complete lack of understanding of what we all go through. For most of us we do not have the energy to educate them, we do not have the ability to explain. I cannot rewind my life to ten years ago, even though i wish everyday i could. I cannot force the doctors to do what they was supposed to do for me, and i would not of been capable anyhow. But looks like i will suffer the long term consequences.</p>
294	No ME service or unit available in my area.
295	No clinics or support in Northern Ireland. No understanding from any GP. Cannot believe I am still reading headlines querying whether this illness is an illness at all!
296	My son had two failed referrals to a CFS clinic as no one was taking paediatrics, by the time a CFS clinic was able to offer an appointment over one year had passed from first referral and 18 months from illness onset. My son was by that time too ill to attend and was discharged. No letter regarding my telephone consultation and recommendations were sent to my GP. Two and a half years later and my housebound son has had absolutely no nhs support.
297	There aren't any M.E. Clinics that were accessible. We were referred many times only to be told we were outside the catchment area and denied.
298	I was never referred on to a clinic? Never saw a doctor! I was diagnosed by occupational health at Frenchay in Bristol and given a leaflet on GETS? That's it. Cheap bloody care NHS!
299	We live in Scotland there is no ME specialist clinics Paediatricians or doctors we do not have virtual education we are treated wrong by so many it needs to change we were refused DLA we get nothing to help us we feel alone most of the time this all needs to change it is soul destroying watching your teenage daughter missing out in her teenage years losing her friends as she is too ill to join in please help. We were referred to physiotherapist the first one did graded exercise which made my daughter worse more understanding and training is needed for medical profession and teachers
300	In Northants, Northampton specifically, there is a diagnosis and then zero input from the NHS at any level
301	It isn't as black and white as increasing or decreasing activity levels. The best approach I have found is to find the right balance between resting, doing, recovering, pacing etc
302	It took me several years to get a diagnosis from a GP and I've since been waiting for months for my hospital referral to come through.

303	<i>There is no clinic near me. I get no treatment. I have been forgotten.</i>
304	<i>There are nowhere near enough specialist services</i>
305	<i>St James , The Beeches . Portsmouth</i>
306	<i>I wish there was more information for doctors so that I would have correctly advised on activity levels and would not be housebound now.</i>
307	<i>No</i>
308	<i>I was given little advice because it was nearly thirty years ago and it was a difficult illness to diagnose. It followed a bout of glandular fever and at first was given the name post viral fatigue syndrome, later followed by ME, now mecfs.</i>
309	<i>Yes in Wales no me services exist and gp would not take on care either so we were forced to seek alternative therapy left without a consultant or gp. We were told once 16 years that rheumatology should take on our care but they refused so bar diagnosis which took 3 years there has been zero care. Even when bed and house bound and living in sensory overload in a dark room no one would visit or help or care this is a scary place to be and to be told your illness is contentious is ridiculous and heartless. Wales needs to sort out there attitude and care. And for all to know what's available and to take a keen interest. Being disbelieved is a huge set back. Once you meet and alternative therapist who cares healing begins but a a huge financial cost which is not right at all.</i>
310	<i>This survey doesn't take into account those severe patients who couldn't attend a clinic but did have ME/CFS service input</i>
311	<i>I have never been offered a place at an ME/CFS service and was told by my doctor the waitlist was too long so there was no point</i>
312	<i>All doctors seemed to equate ME/CFS with just general fatigue. They seemed at a loss. One apologised and said they don't know what causes it or what to do about it which was helpful. Others just gave the impression it was psychological and due to my childhood trauma.</i>
313	<i>I find the blanket advice of this is a chronic illness. There's "nothing" we can do a bit like a cop out. Oh and that every other illness or symptom is just put down to ME ahh that's your ME no further investigation.</i>
314	<i>The advice was: " only do half as much as you think you can do". My condition has still deteriorated but I haven't collapsed yet. That's coming soon after 36 years.</i>
315	<i>I have felt largely ignored and forgotten about by the the Health System. Over 19 years after my diagnosis i have yet to receive consistent care and often have to do my own research and beg to referred to other services.</i>
316	<i>A year after approaching my GP with fatigue I am only just on the waiting list for my nearest Chronic Fatigue Service. It will be another year before I see anyone. In the meantime I'm under the pain clinic who advocate graded exercise, which makes me worse.</i>
317	<i>I was diagnosed about ten years ago but after the diagnosis appointment and advice given then I was offered anything as a follow up. I have gained my advice through reading up on it and trial and error of what works for me.</i>

318	<i>I have received NO treatment from the #nhs beyond 5 years of anti depressants that actually made me suicidal. I have several other conditions and to ensure that these get treated I never mention the dx of ME because when I have in the past my symptoms have been immediately dismissed as some sort of health seeking behaviour and an immediate assumption is made that I avoid activity. I wanted to be patronised my first stop wouldn't be the NHS. I was once offered and in patient programme that was immediately rescinded because the consultant decided that I would be a disruptive influence, put simply I would not submit to the notion that this is in my head. I feel that despite the NHS acknowledging it is a physical condition medical professionals are still teaching that we are needy malingerers best to be disbelieved.</i>
319	<i>We have been referred to Bath pediatric CFS service and signed up for an online trial but there is a long wait to start with any treatment. Diagnosis in July still not been seen by specialists as of 5oct and no word as to when we will start</i>
320	<i>Diagnosed thirty years or so ago at 11, sort of recovered by 20 to the point I could do 6h/day of stuff. Tried to push and do more, ended up at 1m now.</i>
321	<i>la mayoría de los profesionales no conoce la enfermedad</i>
322	<i>I had NO knowledge there was an ME/CFS Clinic locally and shall ask for a referral! I have a definite diagnosis, 3 years of no improvement and have lost my life, my identity and my confidence.</i>
323	<i>I got diagnosed with it in 1999 but the dr didn't explain what it was only found out what it was from the internet. All the information I have comes from charities. Drs give me Co-codamol 30/500 without a problem which I'm grateful for. But I have no check ups and no regular appointments. And feel like I have been left to work this out on my own.</i>
324	<i>I was told by two separate GPs that they didn't believe in ME. I have never been offered an ME Clinic or anything other than antidepressants or that they can't do anything about ME.</i>
325	<i>I don't think there is enough consistency around care for those suffering with ME and CFS. Some GPs are really good others don't seem to really acknowledge it and the same goes for the general public the lack of awareness is astounding</i>
326	<i>2000. Offered appointment at [a professional's] clinic. 18 month waiting list. too ill to travel. Spoke to London registrar who said no facilities anyway for severely ill patients. Said look at their website for advice. 2002. Offered local Kent nhs clinic. Couldn't get there anyway but know from nephew with ME who attended they only offer psychosocial help, nothing medical. Going caused PEM for nephew- they do 90minute group therapy. Far too long and impossible for people with moderate to severe ME.</i>
327	<i>I was given diagnosis over the phone by gp who told me to read a book (Daryl Ho Yen) and look it up (ME) on the internet/visit my local library, more than that he couldn't say. When I got back to him with ME Assosiation/Action for ME literature he became very angry and said he/colleagues didn't have time. I'd been "diagnosed" with depression for several years previously , which I didn't agree with and encouraged to try CBT. There was no specialist clinic in my area at the time (2007). I was refused an out of area referral due to costs. We now currently have a "specialist" in ME who is a psychiatrist , who i have no intention of seeing. (NHS Highland).</i>

328

No help from GP, or dietician and 6 month waiting list for CFS clinic. I am house/bed bound now trying to get PIP. There is no understanding of empathy for people with this condition. Everyone says you have to just push through. Before I was ill I was at the peak of health doing hiit training and all sorts. I have never been a lazy person or lacked motivation. Now I have to rely on my partner who has become my full time carer. I sometimes even need help to eat and drink because of this condition. It is debilitating and no-one cares.