



# YOUR EXPERIENCE OF ME SERVICES



**Survey report by  
#MEAction UK**

**October 2019**

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**APPENDIX 6**

## Appendix 6 - Final comments from respondents

All comments have had identifying information redacted.

	<b>Which clinic in the UK did you attend?</b>	<b>Is there anything else you would like to add?</b>
<b>1</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>Once the course ended that was effectively the end of the support offered</i>
<b>2</b>	Salford CFS/ME Service	<i>It's a really mixed bag. Two of the staff were really supportive, even if they were misguided and wrong about most things. One member was downright rude, arrogant and dismissive.</i>
<b>3</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	<i>it should have its named changed to multi dysfunctional disease</i>
<b>4</b>	Wells - Somerset CFS/ME Service	<i>Services are being run by people with no personal experience otherwise they wouldn't push own agenda and enforce positive thinking as a solution. Its a real disease we need to keep well via diet, adjusting our activity not keep increasing it. Discussing exercise with an m.e group is insulting. Need someone who has experience running these services as i really dont think this disease is understood without experience.</i>
<b>5</b>	Not listed	<i>I attended the Glasgow homeopathic clinic which was amazing. I can not attend as my gps practice moved out of Glasgow. Cbt and get were suggested (almost forced on by gp) and made me feel much worse and blamed myself for my illness</i>
<b>6</b>	Nottinghamshire PICS CFS/ME Service for Adults	<i>Just because the programme name isn't GET or CBT doesn't mean it isn't based on those approaches.</i>
<b>7</b>	Not listed	<i>Sussex wide ME/CFS Service are appallingly arrogant, misinformed, have a total inability to listen and still promote wholly discredited GET. They are useless and the service should be abolished and all employees excluded from working with patients with CFS/ME. They are a wunch of bankers 😏😏😏</i>
<b>8</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>The occupational support I was allocated was extremely useful in the management of my condition, not only from the strategies but by providing me with the aids I needed around the home to make daily tasks more manageable.</i>

9	Not listed	<i>I have filled it in as if I attended a clinic, but in fact it was home visits from the clinic OT, as by then (20 years into my illness) I was housebound. I knew more than the OT, and gave up on her completely when she started taking an interest in the Lightning Process. I have since heard that the clinic has strayed into other unevidenced 'treatments'. OT's are not suited to this work - they don't have sufficient medical knowledge or scientific training to be experimenting with very sick people.</i>
10	Harrogate CFS Service	<i>The clinic sent a rude letter to my GP when he and I decided to stop intervention from the clinic because of my worsening condition. That affected how I was treated by other healthcare professionals and was very unprofessional. Patients are supposed to be allowed to have the final say on treatment options. If you coerce them or seek to punish them for making the best choice for them in consultation with their other healthcare professionals then that undermines your patients and the clinic.</i>
11	Bristol CFS/ME Service for Adults	<i>I think the Bristol clinic does an admirable job of teaching people about pacing and ensuring that attendees see the range of suffering that individuals can experience. However, I believe that NHS services should be offering treatments for the biomedical cause of ME/CFS that can lead to a significant improvement in health. The current service is, really, a sticking plaster when what is needed is focussed research to understand the disease and implement true, meaningful, support to sufferers.</i>
12	Edinburgh - Lothian CFS/ME Service	<i>A diagnosis needs to be clear with an explanation. It's easy to think someone is telling you that you are tired when fatigue is mentioned. It's not clear that it is recognised as being disabling or long-term.</i>
13	Bristol CFS/ME Service for Adults	<i>The M.E./CFS services made me feel partly responsible for having this condition. They believe stress is a contributing factor in getting M.E. This may be true, but I feel now like the illness causes severe stress/tension even if I do my best to relax.  I also dislike the term Chronic Fatigue Syndrome. There are many more symptoms than fatigue. M.E. is better suited.</i>
14	London - University College Hospitals Children and young people's specialist adolescent services	<i>We are 'lucky' my daughter is stubborn and said very clearly she did not want 'psychology' as she knew this would not help her get better. We had also been warned about graded exercise therapy and my daughter knew this would not help her get better either, she is a bright girl, and found it easy to say no. We were not pushed because of these reasons, but anyone not so sure could easily be as this is how the illness is viewed. Instead my daughter had 'Activity Management' and was continually told to increase activity, even on a bad day when she was barely able to get out of bed and symptoms were severe. My daughter did not push herself to go for a 5 or 10 minute walk on those days because she knew it would make her feel a lot worse. The clinic were helpful with sending a letter to school so we eventually got home tuition, and also they supported my daughter to get disability allowance and an ECHP. Just not actual symptoms unfortunately - this needs to change as when you are first diagnosed you don't know much about the illness and need the right advice - pushing to do more is the wrong advice but we find that out the hard way, some children are permanently damaged and made far more ill by these recommendations. GET needs to be removed from the NICE guidelines immediately!</i>

<b>15</b>	Not listed	<i>The whole system needs overhauling. GET and CBT need throwing out and replaced with biomedical research.</i>
<b>16</b>	Bristol CFS/ME Service for Adults	<i>Although the CBT and GET strategies that I was taught when I was first ill helped me to increase my daily activity a certain amount, over all I think my health has worsened due to pushing my body beyond what it is capable of.</i>
<b>17</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Following GET/CBT caused a huge decline from relatively mildly affected to housebound/bedbased. I have not recovered from that.</i>
<b>18</b>	Not listed	<i>I have had this diagnosis for 2 years and anything I know about it is purely down to my own research. The Physio at the clinic I attend in Glasgow has been extremely understanding and helpful however my GP knows nothing of my illness and symptoms and it has gotten to the point I just won't go to see him no matter how bad I get as there is literally no point and I just leave feeling stressed which I have learned does not help my symptoms. There needs to be more training on CFS/ME for the regular GPs.</i>
<b>19</b>	Bristol CFS/ME Service for Adults	<i>I've never felt so belittled as by the Dr I saw there, I was in floods of tears after she spoke to me and she just got up and opened the door. Also, the service isn't fit for purpose if it can't be flexible over being too unwell to attend ( I had phoned to cancel beforehand with explanations).</i>
<b>20</b>	Nuneaton - Warwickshire CFS Service	<i>Only that I attended a different CFS clinic when first diagnosed 15 years ago (Addenbrookes, Cambridge) and as far as I can see nothing has improved :(</i>
<b>21</b>	Fareham - South Coast Fatigue	<i>This disease has two burdens. The illness itself and everything it robs you off, then there is the stigma attached to it. This doubles the pain of the illness. Not only do you have to deal with your symptoms and a shockingly poor quality of life due to your disability but you have to deal with people not taking your very real disease seriously. It is even more appalling that this applies to medical professionals. We are not supposed to be the experts, they are. I need my energy to fight this disease, I shouldn't have to waste it fighting everyone to be believed and to receive even the most basic care. There would be outrage if any other group of patients were treated like this.</i>
<b>22</b>	Bristol CFS/ME Service for Adults	<i>The CFS services are under threat of being closed down. The UK ME charities should be helping those CFS services that don't push CBT/GET but encourage Pacing, to secure the funding they need to keep going. Footnote: #MEAction is a very new charity to the UK ME scene and has made numerous erroneous statements about the history of the illness in the UK. They should take their lead from the more experienced ME Association.</i>

23	Nottinghamshire PICS CFS/ME Service for Adults	<p><i>Basing the treatment of ME and CFS upon the discredited and demonstrably false paradigm that there is no physical illness and that symptoms are created by deconditioning and patients focusing on said symptoms is failing patients on a monumental scale. Laboratory based studies are literally disproving this all the time, there are currently 9000+ scientific papers detailing physiological abnormalities in ME and CFS patients and absolutely NONE supporting the deconditioning hypothesis - NONE.</i></p> <p><i>How NICE can somehow legitimately only consider published RCTs on treatments as 'evidence' is beyond ignorance and amounts to abuse of patients and medical neglect. Science is literally disproving the basis upon which these studies are founded - THEY MUST BE RETIRED. Understanding the biological cause and basis of an illness must come before treatments can be designed and tested - we need more biomedical research, not ineffective treatment models that are easily and simply debunked.</i></p> <p><i>NICE MUST consider laboratory evidence for the physical abnormalities found in ME and CFS patients if they are to create accurate and workable guidelines that benefit the patient population. Retire the biopsychosocial model NOW and ACTUALLY LISTEN to the thousands of patients and researchers that are telling you that this approach DOES NOT WORK!</i></p>
24	Essex Chronic Fatigue Service	<p><i>There's a lot but I'm not well enough to go through it. I felt like I had to do GET and CBT, especially as 'there was nothing else'</i></p>
25	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<p><i>There was no biomedical treatment, no testing for frequent co morbid conditions eg pots. All of this would have been useful. When I refused get I was discharged. Now I see no one for my ME.</i></p>
26	London - Royal Free London NHS Foundation Trust Fatigue Service	<p><i>I'm waiting for treatment to restart due to lack of funding in the interim I've worded considerably</i></p>

<p><b>27</b></p>	<p>Edinburgh - Lothian CFS/ME Service</p>	<p><i>The first health professional I saw in regards to my ME was my GP. At the time (before I had been diagnosed) she thought I could have MS so she referred me to a neurologist. By the time that appointment arrived I had been reading up on ME, and I was fairly certain that's what I had. I mentioned this to my GP and she told me it was also a possibility and to ask the neurologist about it. So when I saw the neurologist (at the Western General in Edinburgh) I brought up ME as a possible diagnosis. As soon as I did, her demeanour changed, she said she would not talk about ME and she became hostile towards me. I left that appointment in tears, it was the coldest, most uncomfortable and traumatic consultation I have ever experienced. All she cared about was ruling out MS, which we did. Once MS was ruled out (after getting the results of my brain MRI) and the results of my various other tests came back negative, my GP diagnosed me with ME. I asked her for more information, my prognosis, any advice etc, her answer was to go home and "Google it". That is the extent of the medical support I received at the beginning of the illness that turned my life upside down.</i></p> <p><i>In terms of the advice I wish I had received, along with some other ME patients, we came up with this...</i></p> <p><i>The main tip for someone newly diagnosed is that most people who recover do so within the first two years, and if you haven't recovered in 5 years, then you are unlikely to ever recover*. The moral is: do whatever you need to do in the early years to maximise your chances of recovery. In particular, put money and ambition aside. That can wait, because if it doesn't, you may never be able to do it again. Most people with long term ME pushed themselves in the early years. There is no way that you can do that AND recover. Take having ME very very seriously. The rest of your life depends on it. Pace yourself. Never over do it. Avoid stress like the plague.</i></p> <p><i>If you haven't recovered within 5 years, you don't have to give up hope of recovery (it's not impossible) but you do have to learn to live with it. That's a different battle. Avoid stress, but remember that life is for living, so overdo it if you must, but do so with a plan. Take control of the illness by deciding when you are going to be active and when you are going to be inactive. Have a predictable weekly – even monthly – routine. Expect to be better in the summer and worse in the winter (or vice versa) and plan accordingly. Try and keep an emergency reserve for the unexpected. Have a contingency plan for when your bad days – when you can't do anything – last longer than you expect them to. Have a contingency plan for when your best days – when you can do things with minimal cost – last longer than you expect them to. Do you take the opportunity to do even more? Or do you try to build on your success in the hope of some long term improvement?</i></p> <p><i>Over the long term you will have not just bad days and better days, bad weeks and better weeks, bad months and better months, but bad years and better years. Strive to listen to your body and the rules that you have set for yourself. Contact support groups and share. You aren't alone.</i></p> <p><i>*These statistics were taken from a report published in 2002 by the Working Group on CFS/ME, a group established by the Chief Medical Officer in 1998.</i></p>
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<b>28</b>	Liverpool CFS/ME Management Services	<i>Four years until diagnosis. My GP has no knowledge. Left with extreme insomnia for 9 years, cognitive problems such as memory loss, speech loss in bad periods, low HR, gastric symptoms etc etc weight loss 3 stone. All symptoms ignored. Former High School Science Teacher.</i>
<b>29</b>	Private clinic	<i>Professional norms are irrelevant. Alchemists also had professional norms.</i>
<b>30</b>	Liverpool CFS/ME Management Services	<i>From diagnosis I haven't felt supported. Feel as though I have been left to manage this horrendous, debilitating and fluctuating illness by myself. I have had no advice or support regards to working and sickness and the stress caused by trying to adapt and manage every aspect of life has further exacerbated my symptoms. I've had no real support with regards to which medications to relieve symptoms and feel that GPs do not understand/believe this condition. Something has to change to support the thousands of sufferers in this country alone!!</i>
<b>31</b>	Dorchester - Dorset Children and Young People's Chronic Fatigue Service	<i>the reason i ultimately stopped attending the clinic was because the 45 minute journey each way was adding to my exhaustion. I also was told - somewhat proudly - by the consultant who diagnosed me that he never wrote a prescription for any cfs symptoms (which simply forced me to see my gp for pain relief). what i remember of my initial (and only) appointment with the consultant was that he asked a lot of leading questions &amp; was trying to get me to answer things i didn't really understand (this confirmed by my mother who attended with me)</i>
<b>32</b>	Private clinic	<i>There is no basis in actual science for psychologists or psychiatrists to run or influence the treatment of pwME. This is if we defined science as the deployment of scientific practice, as opposed to merely using the word science. Those behavioural professions have a role in assisting with the pressures of being chronically ill, but that point also applies to and is no different from cancer, strokes or other non somatic afflictions.</i>
<b>33</b>	Bristol CFS/ME Service for Adults	<i>M.E. is not a psychological illness and therefore an approach which included GET and CBT is harmful. This I found to be true - to my physical cost.</i>

<b>34</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>When I first saw my GP, they suspected ME/CFS but gave me no advice whatsoever. This lack of advice actually led to a rapid deterioration as all the information I had came from NHS online sites and info on CFS about it being due to anxiety/psychological causes, how GET is an nhs treatment. So I actually continued just doing the same activity I was doing despite being so unwell and getting worse - after all, if it was dangerous to do so, wouldn't my GP have told me? That's what led me to go from mild ME to severe ME within a matter of months. During that time my GP didn't do anything except order some blood tests and then refer me to a rheumatologist. I know that if I had been told immediately by my GP to rest, when I was mild, i would have dropped out of university then and stabilised. and I would not be in this position now - where I cannot speak much, cannot move unaided and cannot even sit up or eat by myself. It has done me so much harm and please NICE guidelines don't let this keep happening to people.</i>
<b>35</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>Staff had good intent, but were obviously misinformed from bad guidelines which were ultimately harmful. Complete lack of any access to a specialist is appalling. Lack of online/phone appointments for often house/bed bound patients is ridiculous, as is discharging patients for missed appointments given the unpredictability and nature of this illness</i>
<b>36</b>	Edinburgh - Lothian CFS/ME Service	<i>It took years to get a diagnosis which only added to the stress. I was told repeatedly by GP's that I had tonsillitis. Eventually I chose to pay privately to see a Consultant immunologist who gave me a diagnosis. If I'd known I would have rested at the beginning - I've now had ME for the ten prime years of my life - 20 to 30 and it's soul-destroying.</i>
<b>37</b>	Manchester CFS/ME Service for Children and Young People	<i>dreadful ME services at Manchester Children's hospital. led by psychiatric nurse. No appropriate management or services, Harmful advice caused worsening. They document that a refusal to agree to forced incarceration for bipsychosocial rehabilitation in a tier 4 psych unit specialising in pervasive refusal syndrome ( Galaxy House) would lead to child protection proceedings...court proceedings and it did ...instantly. Should be closed. I know others who have attended heere and been accused of FI when really ill with ME.</i>

<b>38</b>	Not listed	<p><i>The clinic I used was defunded as it didn't use what is now considered a standard NHS treatment plan. It helped me improve and sustain a better level, although I was never fully cured. I have since relapsed and because the clinic I had previously attended is no longer available, I am still ill and have been for the decade since my relapse.</i></p> <p><i>The treatment of MECFS in the UK by the NHS is appalling, it is inaccessible for many of us as it doesn't have an outreach facility, the 'treatment' it does offer is utterly inadequate and mostly detrimental, there is no facility to prescribe medications that have been shown by research to make a difference in a number of individuals with MECFS, it is only a one size fits all service which does not work for the majority of genuine MECFS patients, and the testing for differential diagnoses is so limited that it's more or less useless.</i></p> <p><i>The MECFS patients in the UK have been horrifically let down in the UK, 6 members of my family alone have lost 3 decades of their lives so far and been treated like animals because we have MECFS. Two of those people have died without ever getting the treatment they deserved, and I firmly believe that they would have had a better chance at still being alive now if the treatment of MECFS in the UK was at the better level that is offered in other countries.</i></p>
<b>39</b>	Bristol CFS/ME Service for Adults	<i>I'm 60 years old and have had this illness since around the age of 15</i>
<b>40</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>A lot of advice given is only doable if you are in an environment that allows you to do it.</i>
<b>41</b>	Bath Centre for Fatigue Services	<i>I think the current system of management is unacceptable. I want to get better, it's a ridiculous idea that an illness would just be ignored and not researched into. We are people. I want treatment. I want to get better.</i>
<b>42</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<i>About time the UK caught up with the latest biomedical research from the US. Given how similar ME symptoms are to numerous other auto-immune diseases, which are treated with respect and compassion, there is no excuse to continue to treat ME patients as if we are to blame for our physical illness.</i>
<b>43</b>	Bristol CFS/ME Service for Adults	<i>One of the main problems with CFS in my experience is a total lack of understanding from anyone in the healthcare and government departments. It can be impossible to maintain a full time job and yet it is expected of us with no medical grounds to challenge this. This causes consequences for both mental and physical health and makes it less likely for a patient to be able to recover and eventually increase their activity levels back to a "normal" amount.</i>

44	Norfolk and Suffolk ME/CFS Service	<p><i>The biopsychosocial model of ME has caused me irreparable harm and suffering for 10 years. I hate it (to put it frankly). We need a biomedical approach from now on, delivered by medically trained physicians who understand the complex pathophysiology of the disease and provide appropriate biomedical monitoring, assessment and treatment. No more 'just mediate 10 times a day and you will recover' or 'you know your thoughts can affect how you feel' rubbish. The current approach is beyond patronising, is extremely outdated, and is just plain inaccurate when compared to what we know from the latest biomedical research.</i></p>
45	Torquay - Torbay and South Devon CFS/ME	<p><i>Due to the Torbay ME/CFS service not having funds to provide care or home visits those who are housebound due severe ME/CFS, they discharged me, with no specialist care since 2017. The service also lacked total disability accessibility awareness, they initially couldn't understand why I was too ill to their centre for an assessment and had to fight for a home visit.</i></p> <p><i>I remain totally housebound and virtually bedbound, especially due to deterioration caused by inappropriate hospital care, in appropriate medications and the stress of having to fight for and overexert to get any NHS care, social care or benefits.</i></p> <p><i>I have increasing debilitating symptoms; it is extremely difficult to even get GP care and blood tests which take months, let alone access to other any investigations. I have no analgesia or medication for mast cell reactions which causes me severe distressing symptoms and further deterioration. And Health and social care professionals also continually ignore wearing fragranced products when visiting my home trigger severe mast cell/allergy reactions and causes me additional severe long term deterioration.</i></p> <p><i>My only consultant care is in London (hundreds of miles away from Devon where I live) as [this professional] (PoTS) and [this professional] (Dysautonomia urology) have kindly agreed to telephone appointments.</i></p>
46	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	<p><i>I felt that meeting others going through similar experiences was the most rewarding part of the clinic. Decreasing my activity just made it harder to get back to the level I was at. Its a fine balance.</i></p>
47	Bristol CFS/ME Service for Adults	<p><i>The sooner we can get rid of the madness of CBT and GET for ME/CFS the sooner we can protect newly diagnosed patients from having their health wrecked. We patients should never have had to go to such lengths to fight off this bad science and the fools who have wielded it.</i></p>
48	Leeds and West Yorkshire CFS/ME Service	<p><i>I feel badly let down and angry that this service made my illness worse and contributed to me eventually having to stop working</i></p>

<b>49</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<p><i>The first time I was seen by this clinic, the only dr I saw after the consultant was pushing that my symptoms were caused by anxiety every appointment. I was not given any advice relevant to ME/CFS by this dr. Any anxiety issues I had in the past were treated and managable at this time.</i></p> <p><i>I was not given any practical help relevant to ME/CFS at all after the inital consultant appointment, and after months of no progress stopped attending bc of this treatment.</i></p> <p><i>I was later referred again in 2017 after becoming a lot more ill and that time I was given much better care.</i></p>
<b>50</b>	London - Uxbridge - Hillingdon CFS/ME Service	<i>There is very little understanding of this horrendous condition throughout the NHS and it is incredibly frustrating to have to continually try to explain what it is to qualified medical practitioners.</i>
<b>51</b>	Private clinic	<i>Advised to change diet to mostly carbs!</i>
<b>52</b>	Nottingham CityCare MOSAIC Service	<i>I saw one CBT therapist who had a good understanding of the problems caused by CFS/ME, but after a reorganisation of the service I was referred to two different therapists, one who seemed to have very little or no understanding of the specific issues, the other only seemed interested in target setting and increasing activity levels regardless of my feelings or symptoms. This experience actually made my symptoms worse.</i>
<b>53</b>	Not listed	<i>The whole psychological approach needs scrapping. CFS is a biological physical disease. Rest is absolutely vital to try to avoid harmful deterioration.</i>
<b>54</b>	Bristol CFS/ME Service for Adults	<i>These cbt/get clinics are a disgrace. Every one of them should be closed. The staff have no knowledge of the neuroimmune disorder that is ME, Myalgic Encephalomyelitis.</i>
<b>55</b>	Not listed	<i>Because there are more &amp; more people being diagnosed with this horrendous multi symptom illness, its time the medical profession took it seriously &amp; accepted it is not a mental illness. It has spoilt my whole life, I have never been able to reach my full potential, despite all the so called anti-depressants, CBT &amp; other supposed remedies I have been prescribed/subjected myself to!!</i>
<b>56</b>	Bristol CFS/ME Service for Adults	<i>I welcome the opportunity to provide valuable personal experience of this disease to the NICE guidelines committee as an Expert by Experience.</i>
<b>57</b>	Fife - ME/CFS Specialist Nurse Service	<i>My GP still believes my CFS is psychological</i>

58	Norfolk and Suffolk ME/CFS Service	<p><i>Just that the advice and information given was often muddled and/or contradictory and very unhelpful overall. For example, there didn't seem to be an understanding that even basic activities of daily living could be too much (as most were for me) so that it was actually impossible to 'find a sustainable baseline' in the way they expected but it was just assumed this would be a quick and simple and all the emphasis was on increasing activity. As part of this process I had to fill in an activity sheet at the beginning which had a week of time split up into hourly blocks - this was difficult to complete as I could barely sustain any activity for more than a few minutes and was mostly resting. They seemed to assume that everyone would have a 'boom and bust' activity pattern and the advice given (which was supposed to be based on my own activity chart) was clearly generic and mentioned examples where people were spending many hours out shopping or socializing and then crashing and so suggested breaking down activities into smaller chunks and resting regularly every few hours to improve the situation!! The one really good function of this service was that the specialist OT would write letters describing level of function in support of benefit applications, without which I would probably be homeless, but this was stopped last year and they are no longer allowed to write letters.</i></p>
59	Edinburgh - Lothian CFS/ME Service	<p><i>I feel badly that I have advocated for more education for Doctors, only to discover that they are still being taught a BPS version of ME that advises CBT and GET as treatment for the actual disease. I don't understand why our government doesn't follow the WHO guidance that this is a neurological disease. I have had to give up work and may never work again because I got so much worse after bad advice. Not only should guidance change but there should be a public enquiry as to how this was allowed to happen and compensation for loss of earnings.</i></p>
60	Bristol CFS/ME Service for Adults	<p><i>ME is a serious, severely life limiting illness. It needs serious funding to undertake serious research to work towards finding out what causes ME, what ME actually is &amp; a cure for ME. Hundreds of thousands of us in the UK alone have our lives literally on hold until this happens &amp; we deserve better.</i></p>
61	Not listed	<p><i>Now I'm severe the clinic no longer does home visits - completely abandoned my clinic wasn't listed, it was at Keswick Cumbria, not sure it even exists anymore, still waiting to find out, my consultant was s retiring - Newcastle, no one is replacing him</i></p>
62	London - Royal London Hospital for Integrated Medicine CFS Service	<p><i>GPs need training on how to manage symptoms. People going to the GP with symptoms of fatigue need to be referred much earlier. The support must must must concentrate on what *can* help and not "there is no cure" which is so unhelpful. There's no cure for my chronic migraine either, but they help me work through treatments. A cure isn't mentioned. Ideally mental health help would be provided in the knowledge that CFS ravages your mental health on its own. So to help you to cope with how hard CFS is. It should be very very clear that it isn't a treatment for CFS but that it is in recognition of how hard CFS is. The only person that's really helped has been an occupational therapist. I'd never even heard of this until my appointment. We need many many of these! I expect people who haven't seen one won't ask for one in this research as they don't know what they are. Please take that into account when analysing this research</i></p>

<b>63</b>	Newcastle - North of Tyne CFS/ME Service	<i>Consultant who diagnosed me gave simple advice "don't use energy you haven't got" &amp; that was the only management advice I was given. It was prior to the supposedly specialist clinics being set up &amp; I was diagnosed &amp; discharged. Later I requested to see a specialist physio as my back was becoming a problem &amp; I was struggling to lift scooter parts in &amp; out of the boot of the car. I saw a physio but only after undergoing nearly 2 hrs of psychoanalysis "to see if physio was the best treatment for my back problems" &amp; included intrusive questions about my relationship with my husband. I did eventually see the physio but he just recommended exercises I had been trying to do under my own steam - and then told me to find a baseline for activity &amp; increase from there. ☹️</i>
<b>64</b>	Private clinic	<i>The only option offered is medication when massage accupuncture reflexology and b12 injections all help too</i>
<b>65</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>Follow up and monitoring has been wholly absent and I feel this is because I have been resistant to GET and they have no alternatives.</i>
<b>66</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>After care is no existent.. Even 6mthly check would be good.. Better education to all levels of professionals with regular updating</i>
<b>67</b>	Bristol CFS/ME Service for Adults	<i>ME services and clinical guidelines need to recognise that patients and staff live in a culture where there is a lot of pressure to do productive work and exercise regularly. For ME patients this is often not possible for a substantial amount of time, and this can be regarded as a moral failing by society. My observation is that we need more support to do less, we don't need any extra encouragement to do more, that comes back naturally as our physical health improves.</i>
<b>68</b>	Not listed	<i>I just wish patients were treated with dignity and respect. I now am scared of doctors which is not a great place to be in. Thanks for doing this survey, it's nice to be heard.</i>
<b>69</b>	Norfolk and Suffolk ME/CFS Service	<i>No</i>
<b>70</b>	Bath Centre for Fatigue Services	<i>Given there is no medical specialism, I am reliant on my GP. He is happy to hide behind a wall of ignorance so I get no help or support at all. When I asked for a home appointment (housebound) he said, they are for people who really are ill!!!! It really is a totally hopeless situation. I feel as if I'm just being left to die. I've had ME severely for 25 years and getting worse year on year</i>
<b>71</b>	Bristol CFS/ME Service for Adults	<i>The clinic referenced the PACE trial as showing increasing activity is beneficial. Even if you disregard the controversy with the PACE trial, this is a misrepresentation of what the PACE showed.</i>

<b>72</b>	Bath Centre for Fatigue Services	<p><i>Spring 2016, I was ill but able to walk. Got the train twice to Bath mineral hospital, given activity management handouts. Hour long sessions which made me ill afterwards. Found handouts bewildering because they didn't describe my illness but persevered.</i></p> <p><i>Told to maintain activity levels and slowly increase. Kept collapsing. Was walking my children to school and then collapsing when I got home. Kept losing ability to speak. Stroke-like symptoms. Thought I should rest but was advised not to. Found travelling to Bath increasingly difficult so started having phone appointments. 1 phone appointment every 6 weeks or so. Slowly declined over this time. Winter 2016 onwards increasingly housebound. Lost the ability to walk. Bought a wheelchair.</i></p> <p><i>Made the decision to stop following clinic advice. Complete rest for 1 year. Slowly improved. Still housebound but able to walk short distances, 50 metres before legs go weak. Since been diagnosed with POTS which clinic never investigated. Wish I'd rested completely in the beginning.</i></p>
<b>73</b>	Salford CFS/ME Service	<p><i>As this questionnaire is biased in its questions I should also say that NHS my negligent employer ignored all medical evidence that needed implementing thus exasperated my disease nurses found it funny to put me on late shifts &amp; running around like mad, CBT does not work on M.E (CFS) this is just a cheap abstention of dealing with and not giving CFS proper treatment. As my wife also has CFS (m.e) this is more than a little patronising. Added to this is the wholly negligent and discrimination is across the board.</i></p>
<b>74</b>	Suffolk Specialist ME and CFS Service	<p><i>For a better understanding from other parts of the Health care system. I found that when speaking to other professionals they either thought I was lying or misdirected me.</i></p>
<b>75</b>	Leeds and West Yorkshire CFS/ME Service	<p><i>By the time I got a referral to the clinic I had already worked out 'pacing' for myself so their advice basically just confirmed what I was already doing. A quicker referral would have helped. Also the location was poor; a long way to travel both to and inside the hospital.</i></p>
<b>76</b>	London - University College Hospitals Children and young people's specialist adolescent services	<p><i>The present management of ME if the UK is dangerous for everyone, especially children and young people and causes immense suffering.</i></p>
<b>77</b>	Bath Centre for Fatigue Services	<p><i>I was told by my work's Occupational Health provider (BUPA) to exercise and it made me significantly worse. The NHS fatigue clinic had a better understanding of the importance of pacing and finding a manageable baseline level but ironically they didn't listen to my concerns about attending the clinic and the physical strain of going each week helped bring on a huge crash that, combined with the damage done by BUPA, left me bedbound for over a year. I feel very let down by both the private and public health sectors.</i></p>

<b>78</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>Local clinic and GPS should be willing to discuss tests administered at a private clinic so that everyone is working together. I felt I had to hide the fact that I had sought private help. I really had to after my awful experience at Derby; just travelling there as a passenger caused a huge crash and being expected to talk for two hours whilst an OT ticked boxes was ridiculous. Still feel let down by NHS.</i>
<b>79</b>	Not listed	<i>I feel that the NHS doesn't review and continually assess your condition and you are just left to fend for yourself, there is no support over the years, you feel totally isolated.</i>
<b>80</b>	Essex Chronic Fatigue Service	<i>There was no need for me to go from mild to severe, I'm angry that people who should have known better didn't act with integrity or honesty, and I'm angry that there is no accountability. No accountability for bad doctors, for rude doctors, for bad "scientists". And there is no way to report harms, like with drugs. When I became severe I had to move from Essex back to my mum's home in Edinburgh. I am fairly confident that my leaving [professionals] care will have been put down as client better now and no longer in need of the service in their statistics, or just not recorded at all. How is that ok? I was so badly harmed by this, but then too ill to take that any further. What about all those who came before me and after me, who was safeguarding them?</i>
<b>81</b>	Bristol CFS/ME Service for Adults	<i>The clinic has not told me to increase my activity levels purely as I seem to have a progressive form of M.e even though they refuse to acknowledge its progressive in nature. They also know I am aware of the many people's lives that have been completely and permanently ruined by G.e.T. They would have otherwise got me to do what they claim is "safe G.e.T". Obviously, G.e.T being based on flawed theory and flawed evidence, there is no such thing as "safe G.e.T". It's either UNSafe G.e.T or not G.e.T at all!</i>
<b>82</b>	Edinburgh - Lothian CFS/ME Service	<i>The medical profession have to get better, this is not ok. And why is there no way that I can report harms from a psychological treatment?</i>
<b>83</b>	Torquay - Torbay and South Devon CFS/ME	<i>Just that I found clinic unhelpful stopped going after 1 attendance, have had to do own research, had to see private consultant to get help. GP no help. Just left to rot really. Only my POTs specialist has been helpful, understanding and offered treatments which have helped and I had to bring the possibility of POTs to GPs attention. If I had been tested right at beginning I could have had treatment right away and had a much improved quality of life and higher functioning, but Nice guidelines discourages testing for POTs, it's disgraceful considering how common it is in ME patients.</i>
<b>84</b>	Not listed	<i>There are no services in my area, the gps are not trained in how to treat patients with ME, so I get no help at all. A lot of the health care professionals feel that ME is psychological so they don't really believe my symptoms and how ill I feel. More training is needed on treatment and medical causes of this illness. Thank god my mum is a nurse and looks after me or I would be alone.</i>

<b>85</b>	York - Yorkshire Fatigue Clinic	<i>Clinics should not be psychology based. Enough research has been done to show it is physiological. More clinics needed - 30 miles to nearest. ALL clinics should offer Skype or phone consultation because if you are moderate or severe you cannot attend even if it is next door. All clinics should be nhs funded. GPs knowledge is woefully inadequate - need specialist nurses like Macmillan nurses to visit and liaise. I've had it 11 months am housebound and Dr has not visited me once. Had to research and find clinics myself which is almost impossible when so poorly.</i>
<b>86</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>M.E patients need to be believed, it is a real physical illness. Last week I visited my gp with severe head pain, she was sympathetic till I said I had m.e, she threw her pen down, rolled her eyes and said I had too much time on my hands to dream up symptoms. I left with a prescription for antidepressants and told to get some work! Where are we supposed to go for help?</i>
<b>87</b>	Nottingham Childrens Hospital CFS/ME Service for Children and Young Adults	<i>The treatment given was from Leicester children's team (no option to choose this). The care received at Leicester was so harmful my child was admitted for tests and was given a CFS diagnosis within 5/7 despite only being 7yrs old. She was readmitted worse and kept in for 6/52. She went from being able to walk short distance to being unable to walk, sit up or hold her head up. She was shouted at and told she was lazy and forced to do intense physio including hydrotherapy. She was made to get out of bed at 7am and not allowed to return until 7pm. The advise and care she received was so harmful and neglectful. 5yrs later she still hasn't recovered, she a full time wheelchair user, tube fed and missed 5 yrs of schooling. Something MUST change, We are under a different hospital now, the care is not harmful but also isn't helpful or supportive. There is nowhere for us to turn to for help.</i>
<b>88</b>	Not listed	<i>please feel free to use my name, [redacted] and state that i am now having to sleep in my own urine as i have my carer removed due to following GET advice.... so no personal care or medications for 12 months of which has not only driven me close to suicide but also means that i have been in total agony since norfolk social services stopped my care as a direct result of following GET.</i>
<b>89</b>	Not listed	<i>The current general lack of awareness of PEM and the dangers of over-exertion means that the risk of harm for pwME is very high from any NHS service. Currently, having no specialist services would be safer than ones based on the current practices.</i>
<b>90</b>	Bath Centre for Fatigue Services	<i>The science is here. There is no need to treat those with ME as if we had a psychological difficulty. Using CBT will not help my high viral titers or help me get out of bed and manage in my home. ME requires a biomedical approach, compassion and social care without stigma. The time is now.</i>

91	Hull and East Yorkshire CFS Service	<p><i>Until it is recognised as a bio medical condition there will be no research and therefore no improvement in the use of certain medications which may help such as medical cannabis and Mestinon and until counselling and carers are provided long term and regularly mental health will not be supported and whilst we are told it is 'all in our heads' our mental health is being seriously damaged. Until research is done so a diagnosis can be found for ME and for CFS then CF caused by other things will continue to suggest that this is a curable illness. I have had it for 26 years and it took 22 years to get a diagnosis. I learnt several therapies and counselling to help myself, looked at lifestyle, diet and activity levels myself without help from the NHS. I know that real CFS does not 'go away' although better periods can occur. I have never been asked to participate in a study or any research. I have noticed that as a woman the perimenopause has made it worse but not been offered any help by the CFS clinic as they accept that hormones does effect the severity but offer no support or solutions. I asked the GP about medicinal cannabis and Mestinon recently but found that no NHS doctor will prescribe either due to NICE guidelines not including these or any other medication even on a trial basis. The NICE guidelines should allow for GP's to prescribe medicines proven to help some people as well as give them permission to offer us help us with practical support such as disability and state aid, carers, occupational health. We should be allowed the same disability rights as anyone else as it is more debilitating than having a limb missing, having medium level MS, Parkinson's or Diabetes or even heart issues. I give you this example: my father is 90 years old and in heart failure, I am 46 and have no 'medical conditions' other than CFS and yet he has more strength, energy, stamina and better general health than I do. I was never able to work more than 24 hours a week and lived in poverty then aged 40 I had a major relapse and have not worked since. I live off the charity of my elderly parents and get no support of any kind from the NHS or any state services because I am invisible - I could not have children due to CFS, I fought to keep my independence but in the end failed to do so. Until CFS is recognised as a medical condition we are all invisible, ignored and stigmatised.</i></p>
92	Bristol CFS/ME Service for Adults	<p><i>You really need to listen to sufferers rather than medical people!</i></p>
93	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<p><i>I wish that the GPs at my surgery had referred me to the CFS/ME service as soon as they realised that I was experiencing post-viral fatigue. Their advice was just to rest when tired - which was not possible to do with my work schedule. They didn't give an indication that my illness might worsen, and might be a chronic condition to which I must adapt in the long term. They were sympathetic, but did not tell me about the specialist CFS service; I only heard about it from a friend, who also recommended a specialist GP at my surgery (to whom I had also not been directed by the surgery itself).</i></p>
94	Bath Specialist Paediatric CFS/ME Treatment Service	<p><i>High turnover in personnel means that differing advice is given, some more supportive than others. Blaming lack of motivation and effort for an inability to improve is unacceptable, especially when other medical conditions go unidentified or treated for over 3 years</i></p>

<b>95</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>Medical neglect and dangerous abusive practice exists which needs. Public enquiry.</i>
<b>96</b>	Not listed	<i>Exercise doesn't help!</i>
<b>97</b>	Not listed	<i>CBT encouraged me to stop thinking of myself as having ME and a serious illness. They said everyone felt tired sometimes and did not accept ME</i>
<b>98</b>	Bristol CFS/ME Service for Adults	<i>Generally I feel I was fortunate in advice received, but had I known where symptoms were heading I would have rested much more in the 12 months before my diagnosis.</i>
<b>99</b>	Nuneaton - Warwickshire CFS Service	<i>I wish GPs knew and understand more about this illness</i>
<b>100</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>The advice and materials given are not suitable for someone with severe ME/CFS and the clinic did not know how best to help someone with my severity of condition- resulting in discharge after worsening symptoms</i>
<b>101</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>Pretty much everything about how we diagnose and treat M.E is nonsense.</i>
<b>102</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>I have since been diagnosed with numerous (incurable) health conditions that cause my chronic fatigue and now actually know how to manage my health. But the process of getting diagnosed with CFS (on the basis of minimal tests or thought from my GP) and sent to a CFS clinic did nothing but delay that process of diagnosis and make me question my own sanity. I don't even think CFS is a real diagnosis - it's just a way of denying people proper medical treatment because it's too expensive and complicated. ME I believe is a real diagnosis but I don't even know if I have that. Even though I meet the international criteria for it, I think it's possible the combination of conditions I have could cause those symptoms anyway.</i>
<b>103</b>	Private clinic	<i>I have had to search and spend thousands in Northern Ireland seeking my own recovery following diagnosis for ME - the support here medically is rubbish and I blame my GP at the start for dismissing me telling me to take a Berroca and go for a run in the park- we need to target GP's more and more thank u for the amazing work the charities do here you need more support</i>
<b>104</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>UK ME/cfs clinics should be shut down. A state sponsored silent massacre.</i>

<b>105</b>	Not listed	<i>[Redacted] CFS private clinic (see website) has also been magnificent.</i>
<b>106</b>	Oxfordshire CFS/ME Service	<i>Great service in terms of being well understood by physiotherapist with good advice given on finding a baseline before implementing any increase of activity. Therapist made me realise I do too much considering my diagnosis. This kind of therapist is hard to find having experienced different services in different parts of the UK. I feel services should be more multidisciplinary offering cardiac investigations, including HR variability, tilt table tests for POTS and autonomic dysfunction and 24hr CPET testing to assess PEM and recovery response. Additionally scans to assess craniocervical instability would be useful to rule out possibility of misdiagnosis with the potential to lead to actual recovery.</i>
<b>107</b>	Norfolk and Suffolk ME/CFS Service	<i>I only had 1 appointment which was for diagnosis- no follow up at all!</i>
<b>108</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>Different approaches for different circumstances/individuals. I think exercise is good and that its the increasing too far or too fast that is the problem, I have started at 10 seconds on a treadmill and increased very gradually to over 10 minutes. Often people don't realise what they are capable of/are afraid to try if not encouraged to, meaning that they never build any stamina even if it is severely limited.</i>
<b>109</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>At present i feel these services add nothing of use to patients and are a waste of money. They need to be scrapped and the money spent on services which are useful to patients.</i>
<b>110</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I was told that pacing could lead to recovery, which is misleading as it ignores the biological aspects of the disease. Nothing was mentioned of these at any time, such as brain inflammation, blunted heart rate, inadequate right heart filling, reduced oxygen uptake etc. The only support I have had has been 2 sessions on pacing. The group sessions I was offered never materialised and I haven't had any further contact since. The centre doesn't really teach people about the illness.</i>
<b>111</b>	Not listed	<i>I attended my GP on numerous occasions following a virulent chest infection, and flu. Had multiple courses of antibiotics and steroids. After a couple of months when i was only getting out of house to attend appointments, and was otherwise bed bound, and not getting better my GP called me her "heart sink" patient. I was encouraged to go out for 2 -3 brisk walks a day. Determined to get better I followed the advice and got worse. Have now been ill for 9 years. After 6 months my sick lines changed from "chest infection" to "PVFS". In frustration I started to do research and asked GP if I might have ME? I was told they didn't want to put a label on it! I then discovered there was a local ME/cfs clinic (Nottingham), and had to fight to get a referral. A year later I attended clinic. Meanwhile I was made redundant from my well paid job, and had to move in with my elderly parents due to ill health. I have been given no helpful advice from any doctor, and 9 years later feel I have been let down by the nhs. If I had been given better advice originally I might have got better.</i>

112	Liverpool CFS/ME Management Services	<i>6 years to get diagnosed, then when I did the clinic made me even worse , pushed me far beyond my bodies capabilities with the promise that I would recover from my deconditioning in their words 🙄</i>
113	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>This was an excellent clinic which I unfortunately had to leave due to a house move. I had every confidence in the staff who were very supportive, and took a very practical approach which was most helpful. They validated my experience of the illness.</i>
114	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I do not feel like activity management is as realistic as it's made out to be. How can you 'calculate' how much energy a task takes, and prepare and plan so that you will not crash. What happens if being at work I go past my 'daily baseline', what do I do ask to go home? all these issues are not considered. Despite following the timetables and grids I found I would always still crash. It's not realistic for many people. giving real support, especially if they can work to me feels more valuable. Counseling should also be offered just to talk about the emotional impact the condition has, as most practitioners ignore how the limitations of cfs/me affect someone's mental wellbeing and the focus can mostly be on 'you must exercise, you are not ill and you must go to work' instead of supporting that individual. I would much prefer a programme that supported all disabled people into part time work and 'normal' life, so they have their independence and have someone who works with employers. Company's are not punished for over working their disabled (and non disabled) staff, the individual is punished for quitting/ loosing their job. There should also be a better system for invisible illnesses in general, that again would benefit everyone. I could go on and on but that's just a few points</i>
115	Not listed	<i>The best advice I was given my a private clinician Dr Ray Perrin in terms of activity was "everything you think you can do do half". Naturally people with ME want to do the opposite, as we constantly want to do more than we can. Even if you can do something at the time it doesn't mean you should as with PEM we may pay for it later that day, days or weeks later. We have to learn to listen to our bodies not fight against them. In the last 13yrs of constantly asking for help from the NHS I have only had one apt with a person who knew something specifically about ME [professional] and that's only because I asked to see him this year. My GP didn't know he existed! He was great and very knowledgable but ultimately could only help offer me drugs to help with pain relief. MS patients have centres for Hyperbaric Oxygen Therapy and electromagnotherapy across the country and we have nothing despite this being the only treatments I have ever found beneficial. We have to pay for EVERYTHING privately.</i>

<p><b>116</b></p>	<p>Not listed</p>	<p><i>Before I was diagnosed with ME, I had been advised by Occupational Health that I would benefit from a fatigue management programme. Ironically the only way I could access anything of the such was to sign up for Job Seeker's Allowance (at the time I was off work &amp; waiting to be given a new placement). I am so thankful that I accessed this, as it was through that that I was put in touch with an Occupational Therapist who ran the ME group programme. She advised me on resting, ensuring I was getting complete rest when resting, on working out baseline activity levels, avoiding boom &amp; bust, &amp; then pacing, modifying activity &amp; grading activity (gradual increase but halting if symptoms worsened &amp; starting from a step back when eased).</i></p> <p><i>If I had not had this advice I would probably have followed my GPs encouragement to get back to work ASAP, which I know would have lead to a deterioration (I was carefully monitoring what activity levels I had been managing over the last few months &amp; how quickly I was managing to increase without causing set-back &amp; how much it took to cause a set-back. I was managing about an hour a day of desk work, managing to increase this daily amount by 30mins each week (any more caused a set-back), but my GP wanted me to return to a phased return starting at 4 hours a day in 7 days time).</i></p> <p><i>In addition, it was only through appointments with this OT that she shared patterns of symptoms that patients with ME had. Through this, I realised the things that perplexed me about my symptoms (as a doctor myself) e.g. the 48 hour delay in PEM, weren't strange, but were being experienced by many others. It was only through this &amp; her pointing me in the direction of the diagnostic guidelines that I realised I may have ME &amp; saw a specialist for evaluation. Without the diagnosis I would not have been able to access information of how best to manage to maximise chances of recovery &amp; to access a community of support.</i></p> <p><i>There is such value in bringing it up with patients as a 'potential diagnosis' before diagnosis has been confirmed or enough time passed to meet the criteria. Management of ME is different to management of other fatiguing conditions in that 'pushing through symptoms' or 'pushing yourself past your limit' not only doesn't help but frequently causes harm. Similarly to how physical activity which is beneficial and acts as a 'wonder drug' for so many health conditions, needs managed with caution in ME. I have heard so many stories of patients who tried to push through in the early stages and rapidly went from mild to severe ME. Early knowledge of the potential diagnosis &amp; signposting them to information &amp; support early on is so essential to try &amp; prevent this from happening. The cost of those who turn out not to have ME having rested more for a couple of months until alternative diagnosis obtained is much less than the cost of those who weren't given a potential diagnosis ending up bed bound for years or decades and needing assistance with personal care.</i></p>
<p><b>117</b></p>	<p>Sheffield CFS/ME Service for South Yorkshire and North Derbyshire</p>	<p><i>Professionals knowledge and understanding of CFS/ME in my experience is very poor and impacts significantly on my condition and any outcomes. I have had a consultant tell me CFS/ME did not exist and a GP sit and stroke his imaginary beard while telling me they could not explain my symptoms.</i></p>

<b>118</b>	Norfolk and Suffolk ME/CFS Service	<i>Absolutely disgusting the way me/cfs children and adults are being treated, from being totally fit to bed bound. With the state of the clinics pushing for activities that have no benefit. No support, no offer of tests without requesting them. You wouldn't treat a cancer patient like this. Nice guidelines totally inadequate for this very complex neurological condition.</i>
<b>119</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The current psychosocial model of treatment is not fit for purpose.</i>
<b>120</b>	Maidstone - Kent & Medway CFS/ME Service	<i>The most knowledgeable and understanding professional I have ever met in my 27 years of being ill is [professional].</i>
<b>121</b>	Not listed	<i>14 years I've had ME/CFS and strongly believe that if I had rested more and gave my body time to heal I would not be so severe at present! I was made to believe I had to keep pushing through. I did this for further 7/8years and believe I'm so much more worse for it . Its soul destroying.</i>
<b>122</b>	York - Yorkshire Fatigue Clinic	<i>My son was diagnosed with P.V.F at first and advised to cut school by half, he improved and made it back to full time school but was having days off sick. Then he was diagnosed with cfs and advised to cut back on school again and increase activity slowly. Then he got glandular fever and became very ill, house bound and has been off school now for 2.5 years. After appeal we secured funding for him to be seen at home by the Yorkshire fatigue clinic. They visit once a month. He is making progress.</i>
<b>123</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>There are huge gaps in services for example post 16 we have been discharged from paediatrics with no provision</i>
<b>124</b>	Not listed	<i>I would love to see doctors nologable on ME/CFS in northern Ireland</i>
<b>125</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The biggest problem is the time it took for me to be diagnosed/referred to the clinic. I was referred nearly 2 years after starting to seek diagnosis/onset of symptoms. Had I been sent to them earlier, in the first year of illness, they would have helped me understand the illness, learn how to pace and rest and I wouldn't have lost my good levels of functionality (which is what happened after following GPs advice to keep exercising and keep going; they were just ignoring me.) The Sheffield ME Clinic are doing their best in this hopeless situation of no real treatments offered by the NHS. They are all very supportive and professional. It was just too late for me to benefit from their service. Still their understanding felt like a tiny beam of light in the tunnel we, people with ME, are in.</i>

126	Not listed	<i>Should have been advised to give up work sooner Eventually I had to do this to get a partial recovery anyway and it would have been much more effective if I had not struggled on. The clinic were good in most of what they did, but it isn't possible for everyone to recover without enough rest. And getting enough rest when you live alone and work is Impossible. Just daily care tasks take you over the threshold of what is needed to get better. This was my second experience of cfs. The first time in 1989, I was able to fully rest and got fully better within 18 months. I was well for 14 years. The second time. I attended a clinic, aimed at keeping me at work, and 15 Years later I am improved but now have POTS, and cannot work.</i>
127	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I would like to see frequent / regular social groups and meetings as part of the service. Perhaps lead by people at the service providing an area and facilities for people with M.E if they are able to go and get that social need met. Many people with M.E are isolated or too distressed, tired etc to be able to make new friends and especially with people who have no knowledge of the condition. Therefore to be able to meet weekly or twice weekly with others in a social setting at the clinics etc will help improve people's mental health and self esteem.</i>
128	Oxfordshire CFS/ME Service	<i>There is a severe lack of understanding of ME/CFS and my GP is not open to discussing pain management as she feels it is 'all in my head'</i>
129	Liverpool CFS/ME Management Services	<i>I went to a specialist clinic 7 yrs from falling ill. The opening presentation, told a group of sufferers that we were sick because of poor sleep followed by fatigue followed by over production of adrenalin. This makes no sense to my situation and there was no evidence provided to support this. My adrenal glands were never tested. My OT wanted to discharge me on my first appointment saying that my coping strategies were already everything they would suggest. I was very ill and desperate for help. The best I got was chats on the phone a couple of times were the OT tried to answer my questions. I never felt that she understood my condition at all. The department is up stairs ans far into the hospital. Very difficult for pwme.</i>
130	Suffolk Specialist ME and CFS Service	<i>We need a biomedical marker and real treatments</i>
131	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>I think there's insufficient support for people trying to manage this complex condition. A series of group sessions is insufficient</i>
132	Leeds and West Yorkshire CFS/ME Service	<i>Loads but to tired to type</i>
133	Manchester CFS/ME Service for Children and Young People	<i>Everyone with me/cfs is different. Different triggers, different symptoms and their treatment packages should be different. Rest is the most important thing when you feel ill, but support is vital to prevent isolation. Patients should be listened to and treatment should be individual.</i>

<b>134</b>	Essex Chronic Fatigue Service	<i>I have found support from the NHS quite terrible. The only effective treatment I have had is The Perrin Technique which is a private treatment provided by an osteopath.</i>
<b>135</b>	Not listed	<i>I was diagnosed by my gp after not recovering from a two week long flu virus that started on the 2nd January 1990 . a year later I was sent to [professional's] clinic in the Liverpool school of tropical medicine . where some clown in a white coat suggested I get a dog and took it for walks . I already had a dog and tried to take it for walks twice a day even though my legs where like jelly and it took intense concentration for every step . over the 29 years of this disease my ability to function has continued to degrade I am now mostly house housebound .</i>
<b>136</b>	Not listed	<i>I have no support at all. GP uninterested which is unfortunate as the clinic is 45 miles away (North Wales). It is not feasible to attend courses and the care I did received was poor and unhelpful and so outputting.</i>
<b>137</b>	Norfolk and Suffolk ME/CFS Service	<i>You really need to listen to sufferers rather than medical people!</i>
<b>138</b>	Edinburgh - Lothian CFS/ME Service	<i>Graded exercise made me worse . Pacing with a strict keto diet is the only thing that has helped in any way .</i>
<b>139</b>	Leeds and West Yorkshire CFS/ME Service	<i>I would like more integration with blood tests and physical tests which I can only currently access via my gp; the ME service offers no access to medical testing and treatment options. it is only talking therapy and this requires more than just thinking myself better and managing symptoms. Mitochondrial testing could be made available and individual treatment packages of suitable supplements .</i>
<b>140</b>	Not listed	<i>There is no help available in my area. Social work has directed me to fibromyalgia clinics/help groups instead. Very disappointed.</i>
<b>141</b>	Leeds and West Yorkshire CFS/ME Service	<i>The help and support for people with ME/CFS where I live is very inadequate and there is very little knowledge of ME/CFS by medical professionals including GPs</i>
<b>142</b>	Not listed	<i>Having a 'professional' voice on your behalf is important as we have no medical proof of illness via tests to prove ME/CFS.</i>
<b>143</b>	Norfolk and Suffolk ME/CFS Service	<i>We all just want to be well and being given the right advice/treatment is the very least we should receive!</i>

<b>144</b>	Preston - Lancashire CFS/ME Service	<i>So much. The clinic in 2012 refused to give me any further support or treatment and dismissed me because I refused to participate in GET/CBT, refused to sign a form stating that I would no longer require any further testing or treatment from other practitioners (that would have prevented me from getting my later comorbid diagnoses of POTS and MCAS, eczema etc), and refused to agree that I had ME because I was traumatised (their claim) when I wasn't, and got ME from a virus. They left me with no support, not even an OT and my condition went from mild to severe. I was forced to do all my own research and be on my own doctor and advocate from my sick bed. I am attending the new clinic and I am advising them myself from my 7 years of research, including the whole sick history of PACE trial and why we are in this disgraceful position</i>
<b>145</b>	Bristol CFS/ME Service for Adults	<i>Due to long travel to course I was unable to attend all sessions.</i>
<b>146</b>	Not listed	<i>I truly believe what we eat and drink helps to improve the symptoms. Need regular hormone checks. Plus have yearly heart monitor or sooner if needed. Plus genetics tests. Plus check for viruses. Need monitoring with neurologists and maybe rumatologist, orthopaedics. Plus get mitochondria tested. Plus allergy tests. Take into consideration families medical history. Monitor gut for any problems. Do not state that it is all psychological and get more research into the cause of the physical symptoms of ME.</i>
<b>147</b>	Birmingham and Solihull CFS Service	<i>any kind of exercise therapy or cognitive therapy that does not address the cause of the symptoms can only assist a very small amount. Without addressing the underlying causes, it is just sticking a plaster on a gaping wound. It isn't going to be all that helpful.</i>
<b>148</b>	Not listed	<i>For them to stop enforcing exercise to patients when they are so unwell. Listen to the patient. Offer all the appropriate tests. Communicate with patients GP.</i>
<b>149</b>	Bristol CFS/ME Service for Adults	<i>The science shows that most/all of us are doing too much ie CPET test results why no science based approach at our UK clinics???? CBT is acceptance and commitment and mindfulness and meditation can help,</i>
<b>150</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	<i>I would like to say that not only do GPs and Neurologists need training and understanding and actually to consult the NICE guidelines BEFORE diagnosis, ruling out all red flags and carrying out all suggested blood tests, but that to educate the entire community of GPs when they only have a 5 minute appointment slot, is simply impossible. I would prefer to be referred to a joint GP-Neurology-Psychology led service which had time to look at a patient holistically, carry out all necessary tests and scans BEFORE adopting a psychological approach. If this had happened in my case, I would not have gone undiagnosed with 2 sleep disorders, a neurological condition rendering</i>

*my bladder useless, repeated and sustained visits to my GP who incorrectly sent me for a hysterectomy instead of a sleep study! My GP surgery has never been and will never be equipped to deal with the complexities of my chronic illness, the neurological community has repeatedly failed to diagnose conditions that fall under its remit and so I am sent to a psychologist who has to send me back to the GP and Neurologists frequently like a tennis ball. This takes time and worsens my mental health because the system is not set up for the multifaceted complexities of the condition. Neurologists don't care, and that is my feeling after 8 years of constant bias and discrimination. They don't care because they are not required to, they send you away to be somebody else's problem or to rot and live a miserable existence. They attribute physical, treatable conditions to your past traumas, even when you have recovered from them and it is cruel and unjust. 7 years of therapy later I am physically worse than ever so some actual scientific enquiry wouldn't go a miss. Also, I have had a succession of nasty viruses, EBV, CMV, Meningitis and another serious virus still unknown, and it seems many people with CFS/ME report the onset of symptoms after such viruses so why do CFS/ME clinics have no experts on viruses? Why, when my GP requested 1 serological test from the current guidelines was it sent back from the lab in Cardiff with the comment that this test was not appropriate for a diagnosis of CFS/ME? My GP then had to quote the NICE guidelines to the lab and state that I had travelled to over 30 countries and had procedures abroad because the lab refused to carry out a blood test based on my diagnosis? I would suggest that even the scientists in the labs do not have knowledge of the NICE guidelines and have bias because of the misconception that CFS/ME is a psychological or psychiatric condition! The serological testing is a good idea, I now know the viruses I have, but what then? Who takes it from there? Who tells me how to live with these viruses, the effects they can have on my life? Nobody. Even the Neurologists aren't interested in the test results. For me, the viral aspect of this is crucial to understanding how we find a cure or an effective treatment. You can teach me every single psychological approach in the book but if my physiology is damaged by viruses then I will not see any improvement and this is what has happened to me. As well as having red flags ignored this compounding my symptoms and rendering my quality of life as barely existing. The UK wide approach to CFS/ME is highly stigmatised and because of that people like me are suffering beyond what is reasonable. I hope NICE listens to people with ME and advocates for a totally new approach. I feel like this is a diagnosis of condemnation with very little hope of understanding or recovery, it feels like a terminal diagnosis and at 28 years old I became terminally ill. I was told by a Neurologist flippantly in a 5 minute informal chat, that I have a CFS/ME diagnosis, had I known in the years to follow just how badly this diagnosis would affect me, not the illness, the diagnosis, the discrimination, lack of proper scientific enquiry, the prejudice and bias, I might have opted for euthanasia. I don't say that lightly, life is a precious gift and prior to my contracting meningitis I had a full and healthy life, a career I loved, and now I spend my days in bed, wearing nappies, using walking sticks and a walking frame, and repeatedly being sent for therapy and counselling as if my mind is the problem when the real problem is the scientific community. This diagnosis needs to be taken off the scrap heap and elevated alongside other serious illnesses such as cancer because it is killing people slowly. While the myth that this is all in my head persists, my life drains away every day and the irony is my mind does start to deteriorate and I do feel depressed but because nobody is fighting for my right to life, for my right to proper scientific enquiry*

		<i>and biomedical research. I don't know how I can express myself more clearly than that. And experts can give their opinion but my expertise comes from living with this illness for some 12 years now. The first 4 years I was in Australia and they seemed to handle me without bias, but when my symptoms became debilitating and I returned to the UK, the last 8 years has been the worst years of my life. I have all but given up on the scientific community. NICE has an opportunity here to correct some very bad misconceptions about CFS/ME and to try to save lives, I hope that opportunity is grasped with both hands and that my expert opinion has at least some credibility. I don't expect much these days, in fact, I expect to have to battle every single day of my sad little life to be heard, and to be treated because it seems nobody is listening, and worse, nobody cares.</i>
<b>151</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	<i>I found the clinic misleading and manipulative</i>
<b>152</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>Dr Myhill does a blood test that shows mitochondrial function and proof of fatigue. If this was available it would really help get benefits. Her protocol of treatment should be followed on the NHS.</i>
<b>153</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Most important is compassion and believing my symptoms are real</i>
<b>154</b>	Leeds - Yorkshire Centre for Psychological Medicine inpatient care	<i>ME / CFS is a diagnosis of exclusion. It would be advisable to list the conditions that need to be investigated thoroughly before giving a diagnosis of ME / CFS, e.g connective tissue disorders, Chiari, syringes, Tethered cord syndrome, Intercranial hyper / hypo tension, neurotoxicity e.g mould toxins. It would be advisable to state what methods of testing are most appropriate for each condition to be ruled out. For example, to detect connective tissue disorders, genetic testing may be required. To detect structural abnormalities, upright MRI or weight bearing imaging shows the body under its normal stressors - gravity.</i>
<b>155</b>	Bath Centre for Fatigue Services	<i>This was my second visit to that clinic.. i was also seen in lancs clinic in 2010 who forced CBT/GET by nurses but consultant was awesome and told me to discharge myself</i>
<b>156</b>	Not listed	<i>I don't expect this will be of any use. PWME fully expect NICE to ignore anything they say as they have over previous years and listen to the clinic at Bath who they seem to have an abundance of on the panel which feels wrong and unfair instead of having a balance of those who have supported people with ME for years like Nigel Speight and William Weir.</i>

<b>157</b>	Leeds and West Yorkshire CFS/ME Service	<i>I have had CFS/ME for 17 years now and I still don't feel we are believed/understood by healthcare professionals, they still use the same plan fits all approach and that is the worst approach as we all differ so much. I wasn't diagnosed for 4 years and in that time was told over and over to push myself, increase my activity and push through the pain/fatigue etc. I was given CBT and graded exercise over and over even though I kept telling them it was making me worse. Now every year that passes I get worse and worse, new symptoms arise, pain is worse and so is both the physical and mental fatigue. My GP has no idea how to help me and has admitted that, we still aren't believed by health professionals, general public eye and have the only illness that seems to change its name all the time. I am however eternally grateful to people like Jen, the unrest team and MEAction for doing all you do to try to help people like ME, thank you so much</i>
<b>158</b>	London - University College Hospitals Children and young people's specialist adolescent services	<i>What I had learnt at UCLH I was able to apply when I started under Dunstable 18 months later. I also have postural tachycardia syndrome. UCLH had moved me forwards to return to school but my symptoms return and as now 16 I had to go through the long process of being referred. It took a year to my first CBT appointment.</i>
<b>159</b>	Penrith - Cumbria Persistent Physical Symptoms Service	<i>The treatment for ME should be the same across the UK. No more postcode lottery or wishing I lived in the USA where they have more treatment that is actually effective.</i>
<b>160</b>	London - Uxbridge - Hillingdon CFS/ME Service	<i>My clinic didn't seem to understand that coming in to see them was exhausting and I had to plan sessions around other commitments (kids/appts). I saw a physio there whose advice was sensible but he v much had the idea that exercise helps build fitness for everyone and I'm not sure if that's true with ME. I didn't feel fitness was my issue as my walking would improve/deteriorate suddenly rather than gradually. His ideas in general didn't seem based on ME research. But he didn't pressure me to increase my exercise quickly and was supportive.</i>
<b>161</b>	Preston - Lancashire CFS/ME Service	<i>I am in my 12th year with m.e, and I feel like I have been left to rot by the medical profession.</i>
<b>162</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I found that the cfs service was helpful. However it was the GP care that caused my symptoms to worsen. It took 3 years to get a diagnosis/a doctor that understood. In that time I was advised to do more, add in exercise, it was because I was a new mum and that it was in my head. This made me worse and feel that if I had been taken seriously I would have been better able to recover.</i>
<b>163</b>	Not listed	<i>Since diagnosis in 2011 I have not received help from specialists and have had to manage my illness alone. I now also have fibromyalgia and have found it so difficult to get help I am paying privately</i>

<b>164</b>	Nuneaton - Warwickshire CFS Service	<i>So much to add but not sure how or what but your welcome to contact me at [redacted].</i>
<b>165</b>	Wells - Somerset CFS/ME Service	<i>I was lucky to be diagnosed quite early. But i spent 6 months going to different gps which resulted in a false diagnosis of health anxiety. This made everything worse as i thought i was loosing the plot. Gps need to be educated and have a better understanding of the condition as most don't believe in it.</i>
<b>166</b>	Nottinghamshire PICS CFS/ME Service for Adults	<i>Currently, genuine professionals wanting to help people with ME have to fight against the system to do so. This needs to change, immediately. Professionals should be backed up by guidelines which firstly do no harm, and secondly reflect up to date knowledge and research and patient experiences. This includes recognising that patients are all different, M.E. seems to be a spectrum, not a level, and that most of us are dealing with other conditions at the same time. Politics and budgets should have no place in diagnosing illness.</i>
<b>167</b>	Private clinic	<i>On my initial diagnosis via the NHS I was prescribed GET and CBT. This was in 2012 when my symptoms were not too bad. I began to go downhill in 2017 and have had two periods of long term sick from work. I have not quite reached the crash stage but feel I have been close. By taking the tests suggested by the Optimum Health Clinic I have found out so much about what is going on in my body. I have various viruses, bacteria, toxins, mycotoxins and had SIBO at one point. I follow a supplement protocol based on my symptoms and have made many dietary adjustments. Needless to say I have paid quite a lot of money to get this far but I think that if the NHS could provide even some of these tests then it would possibly help a lot more people.</i>
<b>168</b>	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>The most difficult part is finding complementary and nhs services outside of the me clinic that will make home visits. No-one understands that being bed bound means exactly that but doesn't mean you don't need help</i>
<b>169</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>We need research into causes and treatments for ME CFS.</i>
<b>170</b>	Not listed	<i>Graded Exercise Therapy &amp; Cognitive Behavioral Therapy should be banned, at best it's problematic, outdated and full of lies and at worst severely dangerous leaving patients with little to no quality of life or function.</i>

171	Wells - Somerset CFS/ME Service	<i>I was given CBT in a different location but this was completely useless as I was told I was doing all the right things anyway and it did nothing to help my mood and anxiety. I then attended a different clinic in wincanton hospital when I was much older (2017) I had improved since my first clinic but had halted progress at about 8 hours of activity a day- but again I did not get anything new from this clinic and was told I was doing well and that they could not help anything else. Very limited treatment in the clinics I've visited.</i>
172	Not listed	<i>meaction must change. it has already done so much damage. it must clarify its purpose. it must serve myalgic encephalomyelitis patients only.</i>
173	Nottingham CityCare MOSAIC Service	<i>I recently saw a new GP who is recently qualified and he was very dismissive of both my experience with increasing exercise and my concerns regarding potential harm, saying it was only a small number. He very much inferred my limits with increasing exercise were psychological, it's disappointing to see even newly Qualified GPs are still not being informed of the issues with GET/misuse of CBT as I had hoped the message was getting out there, was I a newly diagnosed patient I could easily have followed his advice and caused myself more issues. Already as I pushed myself to get back to work rather than rest when first diagnosed this caused a decline in my symptoms and I believe why I never recovered as did not listen to my body, enforced bed rest would have been a better option to keep to 50-70% of what I was able to do rather than being at or over my limits</i>
174	Plymouth Sentinel CFS/ME Service	<i>The GP was the best I have encountered BUT when I tried to access the help he himself offered (support with claiming benefits) the clinic refused to pass on my details to him or offer any way to contact him effectively barring me from accessing any help. I have never been followed up by the clinic. I am unsure why this clinic is getting funding from NHS when they are unable,or unwilling, to provide any help,other than a diagnosis,to patients</i>
175	Leeds and West Yorkshire CFS/ME Service	<i>Funding, funding is required at government level. Research is required now. Please believe patients when they share their symptoms and daily life style, living with this disease is a living hell. Listen to the experts, the patients who are suffering. Consider crossovers with other neurological diseases. Look at the spine and cranial instability. Consider all symptoms as a whole, not symptoms individually. Funding needs to be allocated to the professionals much more quickly; I've had to wait 6 months for treatment at Seacroft Leeds and the same for the In-patient service in Leeds. Stop the ridiculous myths about ME; discuss knowledgeably, this illness IS NOT IN MY HEAD. Research, funding needs to be available and quickly, I was bedridden and now housebound, I was suicidal and thought I was going to die. For months I didn't know what was wrong with me. This is unacceptable to the individuals suffering. Training of GPs in recognising the symptoms of ME quickly. Understanding ME is very different to CFS and Fibromyalgia. Help and care in the home quicker. I live alone and have waited 6 months for adult social care to assess me, not good enough. How much more do you want to know. DWP, PIP, ESA and the job centre need immediate intensive training in understanding ME, they put me through hell to just get what I am entitled to as a disabled person. DWP almost tipped me over the edge. Medication is another area where training is required, I am in acute pain 24/7. There is so much more I could enlighten you with, as an expert in ME, as I am suffering with ME and I know far more about the disease than any of the professionals around me and who are treating me.</i>

<b>176</b>	Not listed	<i>I attended Barts Hospital Domiciliary ME/CFS service in 2006, it was shut due to lack of funds in 2011. It was the first service I could access after being severely ill with ME for 18 years. I was unable to complete the course as we had to take things slowly. The service shut in 2011 and I have had no specialist ME NHS provision since (or any other NHS service) despite continuing to be very unwell with ME.</i>
<b>177</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>Please could you be aware that between us my son and I (we both have M.E) have been made to attend 4 different clinics (we have moved a lot and each new GP seems keen to get diagnosis confirmed by a clinic, I would question whether this is a good use of NHS resources) yet we have never been followed up by any of the services. How is assessment of their worth defined and collated when patients are never followed up?</i>
<b>178</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>I don't think a CBT nurse should be put in the position of a specialist ME/CFS NURSE- they are not the same and the CBT nurse couldn't do anything to help, unlike a specialist nurse- who has been properly trained in ME/CFS. CBT is helpful for the symptom of CFS- depression- but is NOT the cause! Also think more training needs to be given to GP's- I'm still getting eye rolls if I mention CFS- it's difficult to talk about anything with my body without mentioning CFS because I have no idea what's causing what.</i>
<b>179</b>	Not listed	<p><i>I cannot believe that CBT and graded exercise are still being heralded as the only treatments available to ME/CFS patients on the NHS. New patients are completely trusting that these professionals understand the illness and then are being betrayed when these treatments make them worse. It can take a long time for patients to stop trusting and in many cases it is then too late.</i></p> <p><i>We need consultants that listen to patients and understand the physical nature of the illness, even if we are still waiting for the science to give us the definitive biological cause.</i></p> <p><i>The Consultant in Rehabilitation that I saw had some understanding of the condition, but was unable to prescribe anything. This has to change. We need ME/CFS consultants that are allowed to use their medical knowledge and experience to prescribe. This consultant agreed with me that B12 injections can be very helpful for ME patients but could only recommend that my GP prescribe them, which he refused.</i></p> <p><i>These are the things that have helped me the most, none of which, I have been able to receive or even be advised to try by the NHS:</i></p> <p><i>Epsom salts baths - give me a small lift.</i></p> <p><i>B12 injections- have reversed much of my brain fog included stuttering and slurring words.</i></p> <p><i>Ketogenic diet - has given me more stable energy throughout the day, no longer having episodes of hypoglycaemia before meals.</i></p> <p><i>Detox regimes- sauna</i></p> <p><i>Thyroid and adrenal support.</i></p>

		<i>We urgently need the system to change and to support us, not cause us to deteriorate.</i>
<b>180</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>We need biologically evidenced treatment and for there not to be a subtle threat to me or my parents for turning down cbt (which Cahms said I didn't need and I agreed). They tell you that it's in your mind and only they can "fix" you - this is not true.</i>
<b>181</b>	Newcastle - North of Tyne CFS/ME Service	<i>2 of the GP's in my practice don't appear to believe in CFS/ME. I found their approaches to be very stressful and damaging. Thankfully a few of the doctors were very supportive. Once I got my diagnosis and had access to the CFS/ME clinic I was given some advice and support. However I still feel like I've been left to get on with it. I can only hope that the future will bring us better services, support and more research. I have attended counselling services, a course on managing long term health conditions and meditation classes along with a support group which I got all this from my understanding GP. I have learnt more about my health condition and questions to ask via Facebook support groups and my own research. But I can't afford to pay for alternative therapies or supplements due to financial constraints. Even with some of the knowledge I've gained, GP's don't seem to find the need to organise more tests to help me. I feel their knowledge is very limited in regards to CFS/ME</i>
<b>182</b>	Not listed	<i>encouraging GET in any way is wildly unhelpful at best and dangerous at worst</i>
<b>183</b>	Bath Centre for Fatigue Services	<i>ANY so called 'treatment' of ME/CFS should cease until the medical profession understand the illness and have proven treatment(s) that work!! Please consult with the Optimum Health Clinic!!</i>
<b>184</b>	London - University College Hospitals Children and young people's specialist adolescent services	<i>GET is harmful and needs to be looked at in terms of patient reviews, rather than based on a small sample of studies.</i>
<b>185</b>	Preston - Lancashire CFS/ME Service	<i>The help and treatment for my condition are rubbish and need a lot of developing. It's frustrating having this condition with no helpful ongoing support</i>
<b>186</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>Need more research into the disease is a lonely illness to have</i>
<b>187</b>	Leeds and West Yorkshire CFS/ME Service	<i>More help with pain and sensory overload.</i>

<b>188</b>	Not listed	<i>CBT doesn't work if the cognitive symptoms of ME are severe on a particular day, because the symptoms make it impossible to implement. Graded Exercise Therapy makes things worse. Real action and treatment is needed, not trying to fob patients off with CBT and GET as a magic fix, and then blaming the patients when they don't work, or sectioning them when they won't undertake the "treatment", as was the case with one patient who died.</i>
<b>189</b>	Not listed	<i>There are no specialist CFS/ME clinics in Wales. And my GPs were not inclined to help much, if at all. And still aren't</i>
<b>190</b>	Not listed	<i>CBT was useless (completely inappropriate) and exercise, as recommended by my GP, was disastrous.</i>
<b>191</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>So called Professionals have a lot to learn about ME/CFS They need to start listening to the people that have it!</i>
<b>192</b>	Birmingham and Solihull CFS Service	<i>The consultant didn't give any explanation or advice on the condition and a member of his team held a support group that gave some information. I was told here we will never recover. I was discharged and care plan sent to gp which contained nothing except blood results etc. The gp have just left me to get on with it and said most people recover. I was told the longer I don't go back to work the harder it will be. They didn't appear to understand I couldn't physically go to work. More understanding is needed by gps</i>
<b>193</b>	Bolton - Bury and Bolton CFS/ME Clinic	<i>ME/CFS services in my area are extremely poor with little understanding, knowledge or interest from current GPs or specialists in other areas. Indeed the situation has not changed one bit since I was first diagnosed - which itself took 10 years.</i>
<b>194</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I felt like all they had to offer was to suggest pacing but not rest to much. After a couple of meeting, I was told that was it. I felt entirely unsupported to be honest. In the end, I worked out for myself that the only thing I could do that reduced the symptoms was resting. I hated resting (still do), but so far, it's still the only thing that helps at all. I do use some of the basic pacing ideas, but ignored the 'increasing' part as that simply made my symptoms worse.</i>
<b>195</b>	Newcastle - North of Tyne CFS/ME Service	<i>I was taught pacing at the clinic which was the only thing I found helpful</i>
<b>196</b>	Bristol CFS/ME Service for Adults	<i>why is the Bristol me centre run by a person qualified in psychology/psychiatry when it is a physical illness as defined by WHO</i>
<b>197</b>	Not listed	<i>Neither CBT nor GET have helped with my symptoms</i>

<b>198</b>	Oxfordshire CFS/ME Service	<i>I believe that the original GP advice (to exercise more when I was already very active) given 30 years ago was actually ill advised and detrimental in impact. I feel it would have been important to rest at the beginning, rather than push-through ferociously, using sheer will power and conscientiousness, ignoring every signal from my body. Happily a lot has moved on in understanding since the 1980s. I am extremely grateful to the community Oxfordshire ME /CFS service and to my current supportive GP and employer. I feel supported and encouraged to continue doing everything I can to support optimum health, to rebuild my mobility (currently at 700 steps a day, up from 300...and I hold a vision of resuming some level of meaningful work.</i>
<b>199</b>	Not listed	<i>How am I supposed to remember stuff from when I first got ME/CFS when Ive had it 20+ years? How does this help now? Or do you only expect people to have this for 6 months then get better???</i>
<b>200</b>	Not listed	<i>Not even options in your survey, the advice given was great if I didn't work but just not in reality, I work but need more support to keep me working, if I didn't work then I'd get the care I need, no local support outside of work hours, no physio that provides relief for a short period of time, was advised massage for my muscle and joint pain would help but my NHS trust doesn't provide this, I was referred for hydro therapy but the pool has closed so unless I pay privately these services not available to me. When I went to physio I was lectured on how many hours a week exercise I should be doing and told to do a circuit of their gym</i>
<b>201</b>	Not listed	<i>I feel that different illnesses are being put under the CFS/ME umbrella so until this stops happening there's no hope for a diagnosis tool or even cure because we are dealing with different conditions!</i>
<b>202</b>	Private clinic	<i>My clinic is the Optimum Health Clinic in London and I have had excellent care from them. My GP by his own admission knows nothing about ME/CFS. It has been expensive to seek non NHS treatment, but I would have remained bed/housebound without it.</i>
<b>203</b>	Fife - ME/CFS Specialist Nurse Service	<i>The worst advice I got and tried to follow was from pain management who said to find baseline levels and stick to that level of activity come what may - even if deteriorating. I'm sure this has worsened my condition.</i>
<b>204</b>	Not listed	<i>GPs should be better informed about ME in order to stop dismissing people as being depressed or told to get up and exercise so as not to fall asleep.</i>
<b>205</b>	Leeds and West Yorkshire CFS/ME Service	<i>The current clinics only address fatigue. For the many ME patients who have the known co-morbidities of ME eg POTS/Dysautonomia, MCAS, EDS, hypermobility etc there is absolutely nothing. No advice on sleep problems apart from the very patronising 'sleep hygiene'. Total therapeutic nihilism &amp; in many cases very poorly trained, unintelligent staff.</i>
<b>206</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	<i>Please consider making changes to these services. It's time that the health care system actively works towards education and reform with regards to the obvious stigma that negatively impacts every patients lives. I have never met a person with M.E who is satisfied with services received.</i>

<b>207</b>	Essex Chronic Fatigue Service	<i>Not sure if I saw Essex services , but it was a terrible clinic by Colchester General. The nurse sent me away saying I wasn't trying. They also seemed to have zero knowledge of the cognitive impairment I suffer, which is worse than the actual exercise issues. A terrible and damaging experience I believe which leader to permanent disability.</i>
<b>208</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>Please look at the work of Dr Neil Nathan &amp; other american doctors that are leading in biomedical treatment of ME to help inform UK practice</i>
<b>209</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>I previously had CBT at Maudsley and both the psychologist and I agreed that my condition was definitely not a mental illness nor psychosomatic.</i>
<b>210</b>	Essex Chronic Fatigue Service	<i>Tell them CBT and psychological abuse doesn't work for a biological illness. To support the patients better and to listen to the patients, it's our bodies that get broken worse by putting us through bad treatments. You wouldn't expect a dr to break a leg and tell you to walk it better!</i>
<b>211</b>	Nuneaton - Warwickshire CFS Service	<i>I am concerned about the provision for the severely affected.</i>
<b>212</b>	Wells - Somerset CFS/ME Service	<i>This illness is robbing people of their chance to lead a "normal" life. More investment is required to find a cure! I am at my wits end trying to maintain a career to support my family. I am rarely able to spend time with family or friends because, if I am not working, I have to rest and recover before going back to work again. HELP!!!</i>
<b>213</b>	Not listed	<i>More health care professionals need to be taught about ME. I took 3 years to be diagnosed and ended up house bound because I was told to just push through.</i>
<b>214</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The people at the Fairlawns Clinic at Hillsborough (Sheffield) appeared to have no clue about the physiology of the actual disease from which I suffer. They did not appear to diagnose my disease in a structured and formal way, using appropriate diagnostic criteria. In focusing on behavioural interventions and ignoring the underlying physical aspects of the disease, they were barking up the wrong tree. It seemed to me that they were engaged in a self-serving exercise, just to ensure the continued survival of the charade they were involved in. Subsequent developments in the field of M.E. research has proved that I was right to ignore their advice.</i>
<b>215</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>There are no valuable services available to me</i>

<b>216</b>	Not listed	<i>It would be really helpful if there was more active management or at least monitoring of ME symptoms and more knowledge within other disciplines and departments of medicine - eg when I accessed gynae and maternity services the healthcare professionals taking care of me were aware of my condition but had no idea how to support or adapt my care because of it. Also when I saw an endocrinologist about (proven hormonal) weight gain he repeatedly told me that I must exercise more to lose weight and went on about deconditioning even though that is just not how me/cfs works</i>
<b>217</b>	Norfolk and Suffolk ME/CFS Service	<i>Some of the questionnaire was difficult as I'm very severe and the questions were aimed at people with non complex standard ME. there wasn't scope to really address issues around severe ME care or knowledge.</i>
<b>218</b>	Not listed	<i>Educate more GPs and hospital staff about ME as most do not believe in this illness or no nothing about it, it's very frustrating to have an illness that isn't being taken seriously. Also more research is needed to find the causes and treat appropriately.</i>
<b>219</b>	Liverpool CFS/ME Management Services	<i>There are not enough resources and research and these are urgently required, unless we have a miracle cure its too late for me</i>
<b>220</b>	Bristol CFS/ME Service for Adults	<i>The general tenor of the questions takes no account of the variable nature of the condition. The condition varies randomly by the hour, day and week etc. Also variable is ones ability to deal with the constant pain brain fog fatigue etc etc etc. Nor does it question the assumption that what currently is diagnosed as ME/CFS et al is probably not a single condition. I left the course in Bristol not only because I found much of what was being 'taught' by the 'professionals' ill informed and patronising. I was finding the journey from Weston Super Mare to Frenchay Hospital (3 hours by public transport) utterly exhausting. Finally how can there be treatment for a condition (even a single one) whose cause is unknown and which is still regarded by NICE and the DWP as largely 'in the mind'. Do I sound cross ? I have had 17 years experience of the condition which is bad enough in itself. Virtually all of the specialist services have been worse than useless. I have fortunate enough to have several sympathetic GP's including my current one</i>
<b>221</b>	Not listed	<i>I was diagnosed in 2014, after being ill for around 15 years before this, with no idea of what was wrong with me. It was a struggle just to get referred to Neurology (where I got my diagnosis). Since being diagnosed I've received pretty much no help &amp; my symptoms have got worse. What has been offered to me is CBT, GET, &amp; various SSRIs, neuropsychology also wanted me to go &amp; stay in a mental health facility for observation. This hasn't changed up to this year. Pretty much every Dr (GPs, consultants, nurses, etc) have been very poorly informed &amp; not up to date about ME/CFS, &amp; I have frequently had to take information to people I've seen (&amp; generally this has not been welcomed).</i>

<b>222</b>	Bath Centre for Fatigue Services	<i>Some of the options were not appropriate to my experience. First advice should be you take every day being kind to yourself. Plan telephone conversations, bathing and medical appointments. If eating and shopping is an issue, shakes/smoothies are a good alternative although noise of a blender can cause problems. Don't be scared to ask for help, especially with the financial aspects of life. A specialist area of advice on benefits, legal rights for those working and daily living expenses causes stress and anxiety, which exaserbates symptoms and in the early days you don't always know this. I could go on more but the above is what I found most stressful.</i>
<b>223</b>	Preston - Lancashire CFS/ME Service	<i>Current understanding by many nhs staff is that exercise can cure *any* patient, even the disputed Pace trial does not suggest this.</i>
<b>224</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>Everyone is different with this illness and what works for one person does not work for another, you can't just come up with one course of action that fits all. At certain times with this illness you need to rest before you can even think of adding anything new into the mix. I honestly think if I had rested at the beginning instead of pushing myself no matter how I felt (advice by the hospital) I wouldn't have got as ill as I did and still am.</i>
<b>225</b>	Essex Chronic Fatigue Service	<i>I did everything the 'experts' told me to do, deteriorated badly, and was discharged from the clinic because I wasn't improving. When I asked the consultant why she thought I'd deteriorated, her response was that I'd probably tried too hard to get better!!</i>
<b>226</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>Graded exercise is harmful. When my symptoms worsened I was discharged from the M.E clinic as there was was nothing else they could do. This is appalling given it was their 'therapy' that made me decline. I was very unwell for two years after this and have never been able to get back to employment. I also didn't appreciate the courses that the clinics ran that had a lot of patient shaming in them in my opinion. Also the clinic I attended was in the next city to where I live so 20 miles away which is not helpful as just getting there was exhausting. I have not met one healthcare professional yet who understands M.E. properly and I have been ill for 15 years and seen many including GP's, nurses. consultants, physiotherapists, psychiatrists and midwives. More education is needed. Only last week I saw my GP about my M E getting worse and was told to exercise!!! I just despair. People with M.E want help and support and respect. We want our lives back, we want to work. We understand the illness so why can't the medical professionals. It's not that hard - increases l'm mental or physical activity cause relapses.</i>

<b>227</b>	London - University College Hospitals Children and young people's specialist adolescent services	<p>Awareness in schools and GPs to spot children in early stages: repeat throat infections, bugs, absences increasing, taking longer to recover. If it had been recognised for what it was earlier, my son would not be homebound now. Consultations need to be in patients home either in person or via internet. Information re support day to day needed.</p> <p>Unifying charities to all give accurate information.</p> <p>Rest must be first action.</p> <p>Support for carers.</p> <p>Child's school to be given funds for home tuition as soon as diagnosis received. Part time, full time, whatever is needed and patient manageable.</p> <p>Had to fight for 10 months for appropriate education and still not perfect or guaranteed for my child now in year 11.</p> <p>More research into affect of immunisations on people with history of glandular fever or recurrent infections. Vitamin injection to be given with immunisations.</p> <p>Collation of what has worked for sufferers, to see if any common thread for others to follow.</p> <p>Online support group for teens to post messages for advice.</p> <p>A process to give support and aids, during and post formal diagnosis.</p> <p>School pastoral support to offer home contact.</p> <p>Support for siblings.</p> <p>Loads more needs and has to be done</p>
<b>228</b>	Private clinic	<p>People can't understand ME unless they have it, particularly at the severest levels.</p>
<b>229</b>	Bolton - Bury and Bolton CFS/ME Clinic	<p>Bolton ME clinic was excellent. Unfortunately the consultant I saw was struck off for offering advice outside of the NICE Guidelines, this was such a shame, he had a brilliant understanding. I was later referred to the Wigan clinic where I was discharged after being unable to attend my first appointment due to being too ill. My GP has asked me if I would like to be re-referred to this clinic but I have said no as it is obvious they have no understanding of the difficulties we face in getting out.</p>
<b>230</b>	Not listed	<p>Overall the understanding of m.e. In the health and social security areas is appalling and we get told you can recover with talking therapy and exercise which is completely wrong and dangerous.</p>
<b>231</b>	Stockport CFS/ME Service	<p>Ageing process plus the existing ME and menopause - I thought the end of dysmennorhoea and monthly cycle plus natural ageing and it's natural reduction of output would even out the ME symptoms as I could pace more, but that isn't what happens- you simply end up with accelerating disability even if you keep mobile and pace well. Ageing with ME is not being addressed either. My husband has ME too- we got it after bad infection in Jan 1995. Life has been very hard. We feel alone but there must be other couples with it surely? We would have made a brilliant longitudinal study but have had to 'hide' from a critical society, medical establishment, employer and governments for so long. Please remember those who have had this for years- the walking dead. Ageing and it's greater opportunity to rest is not giving the relief we had hoped for - we are simply older with ME now!</p>

232	Leeds - Yorkshire Centre for Psychological Medicine inpatient care	<p><i>I am no longer able to access this service as the contract has expired between the two CCGs.</i></p> <p><i>My teenage son has been diagnosed (April 2019) but there is NO service available to him, rejected by four hospitals and CAMHS; so he is not receiving any support.</i></p>
233	Suffolk Specialist ME and CFS Service	<p><i>You can not give blanket advice about activity levels, at the beginning it js important to totally rest, to listen to your body, to understand that even watching tv burns energy and to learn how to totally rest, but as it shifts to another stage it is important to gently start to move, but never with a set target in sight, always with your body's reaction in mind. I had support from a private physio in implementing graded exercise, i upped by 2 mins a month, moving every other day, however as soon as i reached 20 mins of gentle movement a day i crashed, repeatedly. After the third attempt i stopped aiming for 20 mins, it made me worse. But the best advice i had from her was the help in establishing a base line from where to live from, to implement a fixed resting system which took the decision making away and ensured i did not outstrip my energy levels but from where i could make tiny adjustments depending on the day. I am convinced that any healing i have done over the past 8 years has been as a result of really listening to my body and never being reckless, and many of the alternative things i have done such as work with an m.e nutritionist, (not a dietician). The most damaging thing that happens in the NHS is the reaction, even if subtle and unspoken, which tells you this so called professional has no grasp on scientific methodology and thinks that just because a bunch of psychiatrists have decided, with no scientific evidence, that m.e is psychological it is. It makes you avoid the medical profession like the plague and not seek medical help when you go A Fib, for example, because you know exactly what is going on, but would rather wait 3 days before going to your GP in the hope the heart goes back into normal rhythm, than deal with doctors who have no idea that m.e is a) a range of symptoms (the least bothersome of which is chronic fatigue) and b) think there is no physiological alterations in the body or causes for the illness. This kind of attitude alienates patients and potentially damages our health. GP's need better insight into the wide range of symptoms, POTs being the most commonest and overlooked, and need to start listening to their patients and believing them. Science starts with observation. If you have your fingers in your ears and a blindfold on you are never going to have a solid hypothesis to test, you will only ever be making up the results as you go along.</i></p>
234	Leeds and West Yorkshire CFS/ME Service	<p><i>It's hard for ME clinics to treat an illness when the cause is still unknown. They have to work with the tools they have, since there isn't a cure.</i></p>
235	Nuneaton - Warwickshire CFS Service	<p><i>I had to stop attending when I got too sick. There's no provision for severe ME patients.</i></p>
236	Stockport CFS/ME Service	<p><i>The current treatment is about "managing" your symptoms and trying to address the impact on your mental health. Although I have been able to return to some activity it is not enough. I realise the research into this area has been limited but I am not living a life I am existing and I would like there to be some move towards curing rather than dealing with the impact mentality on sufferers.</i></p>

<b>237</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<p><i>I made the horrendously difficult journey to Derby CFS clinic which involved a hour long drive lying on the back seat of my dad's car wearing earplugs, sunglasses to be patronised by an arrogant neurologist who told my family it wasn't a mitochondrial problem and implied I was depressed with nothing to live for. I had had many relapses before, but after rest I recovered almost compltely. This time I got ill working in the highlands of Scotland, mountain biking 2/3 times a week. I wahad been sea fishing the even before I got ill (kidney stone triggered) and arranged to go mountain biking with new friends at the weekend. I was working with a good friend who was also my boss. Enjoying life, in retrospect, obviously I was overdoing things. Even if I was depressed it wouldn't explain the horrendous symptoms I was suffering. Derby Clinic is run my useless unprofessional people, who make assumptions without any evidence and avoid the biomedical literature at all costs. I understand that the majority of the the clinics are like this.</i></p>
<b>238</b>	Not listed	<p><i>The alternative therapy clinic (The Centre for Integrative Care (CIC)) in Glasgow is where people are sent when medical science has no explanation or treatment for their illness, it is a place of last resort where people might improve by the placebo effect. People are given prescriptions for expensive homeopathic 'medicine'. It is not a bad place and the staff are very nice, and want to help. However unless there is biomedical research to find out the cause of ME and ways to treat it, there will be no cure or actual medical treatment.</i></p> <p><i>Also, people should be being seen in specialist ME clinics, not alternative medicine clinics. For a start, they don't diagnose at the CIC and GP's are often reticent to diagnose, I had to see 3 GP's before getting a diagnosis, this was when I was very ill and found this to be a horrendous experience having to change GP's and spend months fighting to get a diagnosis. If there were ME Specialist Dr's in Scotland, people could, at the very least, get a diagnosis.</i></p> <p><i>The first GP I saw told me I had to exercise more, not even through any programme of GET, but just 'exerciser more', this is awful, dangerous, advice to give to someone who has the symptoms of ME.</i></p> <p><i>I was also shocked to be encouraged to do GET at the CIC. ME is not caused by deconditioning, it is not the same as other illnesses where GET might be of use. I strongly believe that this 'treatment' needs to stop being given to people with ME.</i></p>
<b>239</b>	Penrith - Cumbria Persistent Physical Symptoms Service	<p><i>It is time for all the evidence on ME/CFS being a physical problem to be taken into account instead of the unhelpful and sometimes dangerous treatment patients suffer now.</i></p>
<b>240</b>	Newcastle - North of Tyne CFS/ME Service	<p><i>I think a biopsychosocial approach would be helpful. Biological - continuing research to find out organic causes that can be treated; psychological - accepting illness (NOT graded exposure!!); social - pacing activity, disseminating current research to ensure practitioners/public are aware it is not simply 'deconditioning', psychosomatic, or laziness.</i></p>

241	Not listed	<p><i>The NHS experience of my CFS/ME has been appallingly bad. I have been ridiculed, abused, disbelieved and patronised by many NHS medical staff. One doctor told my husband that I had brought the illness on myself because I worked too hard and wrote a medical report about me saying how prisoners of war in Nazi concentration camps survived if they maintained a positive attitude, saying that now it was also my fault that I was not recovering. One physiotherapist told me to my face that she hated treating patients with CFS/ME or fibromyalgia because they were just fat and lazy and she would rather treat patients with a real disease like rheumatoid arthritis. Now I am just ignored. I receive no medical support whatsoever from my GP and there is zero specialist service in Northern Ireland. Ironic since I was a healthcare worker with the NHS before I became ill. Please, please, do not let the younger people being diagnosed now be treated in the same manner as I was. I have been ill for over 20 years. Open your minds to the fact that CFS/ME is a biomedical condition and invest in research. It is no mystery that effective research has been stopped for decades by doctors paid by the insurance companies and the Department of Work and Pensions to ensure that it is classified as a psychiatric disease, so that insurance policy payments and benefit payments can be denied. It is jt about the money. The PACE trial results were fraudulent and yet their false conclusions are still used to inform medical treatment in the UK. Why? Please help change this, the next patient suffering could be you or someone you love.</i></p>
242	Not listed	<p><i>The latest service I am about to attend for a refresher after 3 years (I requested it through my GP and got on) says that feeling down, angry, frustrated about having ME are understandable feelings that we need help to deal with. Some GPs just reach for the anti depressant prescription pad which I refused.</i></p> <p><i>Also, after a course of help to deal with living with ME, after 12 months there is no more contact and we are left to rot. Follow ups should be offered every 12 months indefinitely and more severe ME patients should be monitored more often indefinitely.</i></p>
243	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<p><i>Many people with CFS/ME struggle with the benefits system as it seem unable to cope the concept of fluctuating conditions; NHS services could be much more helpful in documentation to highlight these issues.</i></p>
244	Bath Specialist Paediatric CFS/ME Treatment Service	<p><i>We have been abandoned by our GP who knows nothing about ME. There is no one at the surgery with an interest. Now we have been discharged from the specialist service we are on our own. We are trying other private specialists and services to try and find something that helps. Chiropractic treatment and allergy advice have been the most sucessful</i></p>
245	Leeds and West Yorkshire CFS/ME Service	<p><i>Feel doctors throwing medication at me as no idea on how to help or manage my symptoms. Complete lack of care and compassion at seacroft me clinic. More alternative therapies should be freely available and m.e clinics or m.e champion at each gp surgery one in each area that travels gp practices regular so patients can attend. Social services with a link who is contactable for help and more research and resting in me desperately needed. I've lost my life , career, family , friends because of this illness:(</i></p>

<b>246</b>	Norfolk and Suffolk ME/CFS Service	<i>The service is limited to 6 sessions only and seems unwilling to adapt from a one size fits all. It's more about appearing to provide a service than really focusing on the needs of patients. No longer supports patients with benefit claims, providing evidence. This is an appalling decision and leaves patients with little or no clinical support.</i>
<b>247</b>	Not listed	<i>Made to do gym session despite telling physiotherapist I have ME, severe post exertional malaise &amp; set me back months. Consultant at pain clinic doesn't believe ME exists. Feel abandoned by NHS, &amp; victimised at work. I am not lazy I am ill, was an active - judo, swam, cycled &amp; walked dogs, life has been ruined, I did not choose this, despair at lack of understanding &amp; training by medical community &amp; the misconception that exercise helps is harming and stigmatising people.CBT ineffective because ME is not psychological.Pip and blue badge system not fit for purpose for people with ME</i>
<b>248</b>	Stevenage - East and North Hertfordshire NHS Trust Chronic Fatigue Syndrome Service for Children and Young People	<i>It should not be a postcode lottery determining whether you get support. There needs to be enough services to cover all the UK.</i>
<b>249</b>	Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service	<i>It seems to me there's a huge need for patient input into health services relating to M.E. . Also, all forms of health service need to be made truly accessible for people with all levels of M.E. . Including, and especially all services related to GP services..</i>
<b>250</b>	Fareham - South Coast Fatigue	<i>CFS/ME Clinics need professionals to understand the the illness before attempting to treat the patients and at present they really don't take in to account the scientific evidence of a biological illness. I feel it's getting worse amongst medical professionals whether it's due to ignorance, wrong education or even narcissism amongst some top professionals. I know this for sure as have paid privately for several different specialist as well as being admitted to hospital on NHS and staying in for a week without any tests or treatment other than some blood tests. Nurses telling me to get up and out of bed every morning even though I could barely move, radio on playing music on the ward from 7.30 am.Then being (gently informed ) as though I had mental health issues that they don't always have the answers and was then discharged. The whole experience has been utterly traumatic and at times torturous. I now avoid medical professionals as much as possible even though I am severe and very unwell. Big changes are desperately needed.</i>

<b>251</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>Add things like nutrition/herbal supplements, acupuncture etc.</i>
<b>252</b>	Preston - Lancashire CFS/ME Service	<i>The Preston service was very supportive and gave me a safe space to express my feelings</i>
<b>253</b>	Not listed	<i>I should like gps to be much more knowledgeable about pacing, POTS and the delayed and cumulative cognitive and physical effects of ME/CFS/FM on the long term and stop telling me to exercise more!</i>
<b>254</b>	Not listed	No
<b>255</b>	Salford CFS/ME Service	<i>Thanks for all the great work you are doing to try to improve the treatment we receive.</i>
<b>256</b>	Edinburgh - Lothian CFS/ME Service	<i>The lack of understanding about the impact of this illness by health professionals , and the lack of any therapies and treatments that help needs to be addressed without further delay</i>
<b>257</b>	Not listed	<i>I have been admitted to hospital twice this year with illnesses completely unrelated to M.E. Both times, no-one in A&amp;E had ever heard of M.E/CFS and only one nurse on one of the wards had heard of it but didn't know what it was. Hospital is a horrendous environment for someone with M.E to be in, but when none of the staff who are caring for you have a clue what an M.E patient is going through with the sensory overload, PEM, brain fog, persistent pain etc (and that doesn't include why they've ended up in hospital anyway), it is a bloody nightmare. More courses for hospital staff so they are aware of M.E/CFS, especially for A&amp;E staff.</i>
<b>258</b>	Liverpool CFS/ME Management Services	<i>More advice is required in relation to managing symptoms whilst remaining in the workplace and not just giving up work and claiming benefits.</i>
<b>259</b>	Penrith - Cumbria Persistent Physical Symptoms Service	<i>Health care professionals need up to date training on ME/CFS. This must include the latest biomedical findings from the leading ME researchers like those who attended the recent OMF working group, ME charities, etc. It is shocking that doctors are so out of touch with the latest findings and continue to diagnose and ill-treat patients based on old and outdated ideas stemming from what has now been very clearly proven to be bad science from years ago (PACE). There is no excuse for such neglect and ignorance anymore. It is embarrassing to the field of medicine and very revealing of how outdated their training and knowledge actually is. And the fact that purpose built treatment facilities are so horribly ill-equipped and just as ill-informed is shocking and quite unacceptable. Those who are meant to be helping us are causing us the most harm. Patients must be involved in the planning of treatment facilities and services, and training of medical professionals, we know what we need, we understand our limits and the effects of this illness, in a way that a healthy person never could. The creation of a purpose built care service must include the input of the people it is meant to serve.</i>

<b>260</b>	Not listed	<i>When I was diagnosed 26 years ago my GP called the illness ME and referred me to an eminent neurologist who knew the illness well. Despite serving many years on a Parliamentary Cross Party Group, little progress has been made, in fact there is deterioration in the system, although my area has a specialist nurse.</i>
<b>261</b>	Not listed	<i>Help us! Stop ignoring the millions missing and treating us as though we aren't alive</i>
<b>262</b>	York - Yorkshire Fatigue Clinic	<i>YFC is excellent at what they do, but it is nowhere near enough. I need real treatments not palliatives. I need access to a consultant (not just an OT or GP) who is an expert on ME, understands ME is a devastating physical illness and has access to treatments, drugs, surgery, clinical trials, whatever is required, to get me well. And who can tell other NHS consultants who may treat me that they need to be properly informed that ME is a real physical illness which must be taken into account / risk assessed when they treat me for other illnesses.</i>
<b>263</b>	Not listed	<i>More money for finding a cure, medicine for the debilitating fatigue, educate Drs and the government. People struggle to get any financial help.</i>
<b>264</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I did receive CBT via my GP practice, not the Specialist Service, subsequent to attending the Specialist Service. Though the input I had was, as agreed by myself and the practitioner, aimed at helping me overcome my resistance to pacing myself, it did see us slipping into trying to increase my activity from the stable base line once achieved, which was ultimately linked to a further relapse in my ME.</i>
<b>265</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>It took me 2 years to be diagnosed, which caused no end of stress. I have no doubt this worsened my illness. Then when I was diagnosed I had so little help. I have found ways to help myself, and I'm fortunate enough to have a very good support network. Without this support I have no idea how I would have coped. This must be so difficult for people without family and friends who can help both financially and physically bringing food and helping with general chores/shopping/admin/getting to appointments etc. There was no support from the NHS.</i>
<b>266</b>	Leeds and West Yorkshire CFS/ME Service	<i>They thought I would be 100% if I followed the course. I am the same 10 years later. I have no support and GPs know nothing about my condition.</i>
<b>267</b>	Plymouth Sentinel CFS/ME Service	<i>Psychologists should have nothing to do with this disease. It is proven by Stanford University &amp; many others that's a physical biological disease. CBT and GET should not be offered. Please keep up with the research for goodness sake. It's ms all over again treating us like we are faking being ill and hysterical</i>
<b>268</b>	Not listed	<i>I had both CBT and GET much earlier. Maybe around 2003. Not at the in patient clinic I mentioned. GET made my symptoms increase and become worse. And I eventually had to stop. CBT was no practical help at all. It helped a bit to talk at first though - emotionally. But was of no physical or practical help.</i>

<b>269</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<i>Staff were lovely at the service, but current treatment guidelines are not working.</i>
<b>270</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The most helpful support I was given was Compassion Focused Therapy, to help me come to terms with living with and managing my illness. Unfortunately it was only for 8 sessions, and with such a chronic illness, patients need long term continuity of care.</i>
<b>271</b>	Leeds and West Yorkshire CFS/ME Service	<i>CBT had only very short term benefit. I felt patronised and that I was being humoured. I am now having telephone appointments with the Yorkshire Fatigue Clinic which is very much better. ( Because they understand ME better and have a better attitude to patients, more respect).</i>
<b>272</b>	Fareham - South Coast Fatigue	<i>I did feel that if I managed to achieve an activity, even once, and even possibly then having post exertional malaise, that my HP counted that as a 'win' and that, for that activity, I had reached my goal. In reality, that was not the truth at all. You do not achieve a goal if you are left feeling very ill for several days afterwards! I felt a positive 'spin' was placed on my report and wondered if that was partially to enhance the viability of the service.</i>
<b>273</b>	York - Yorkshire Fatigue Clinic	<i>I had home visits this clinic is good but what we really need is good medical ME consultants who been trained up to help advise Doctors when dealing with severe and very severe me as it gets very complex</i>
<b>274</b>	Preston - Lancashire CFS/ME Service	<i>When I first got ill no one would even entertain a diagnosis as there was no local help available. This meant my symptoms kept getting worse while I tried to keep working. I have continued to deteriorate despite finally being able to be referred to the local service and had I had decent advice on rest during the initial stages I believe I may not have been as disabled by it as I am now. I really feel that where ME/CFS is suspected that a stronger emphasis on early diagnosis and treatment is a must.</i>
<b>275</b>	Bristol CFS/ME Service for Adults	<i>the lightning process ruined my life, please do not work with them. also, please offer other forms of therapy that aren't CBT because it DOESN'T WORK</i>
<b>276</b>	Bristol CFS/ME Service for Adults	<i>I did not experience any negative impacts from the service I attended, however I was relatively well at the time, I was able to respond to the service as offered, and I had already ten years experience of managing the illness. Despite its limitations I would have found the service as delivered helpful when newly diagnosed but it would have been wholly inappropriate to my health status for much of the subsequent 20 years when I have been markedly more ill.</i>

<b>277</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>I am disgusted that I have visited the NHS ME clinic on and off for over 10 years. At no time was I given a proper programme of treatment involving medical staff. I was told that CBT would either completely resolve the ME or would significantly improve it. It has done NEITHER! I am not depressed nor have anxiety and therefore it was pretty useless. It is like treating a person who has chronic asthma or diabetes with CBT and not give them any drugs to control their condition! It took a visit to a rheumatologist at Guys Hospital who put me on a low dose tablet to improve my pain. This has significantly helped my quality of life! I have had a terrible journey of pain and fatigue for over 10 years. This could have been resolved 10 years ago with the proper intervention of a medical team. Despite complaining of ongoing pain , this was ignored by psychologists and therapists and there was a continual push to use the therapy that they had in place. It was considered that these were the best treatment plans available for my symptoms. It was my own research on the subject that led to me to ask for a GP referral to a rheumatologist which has actually changed my life. There are so many people in my position and there is a significant lack of understanding of the condition across the medical profession. It is a disgrace that the treatments have not been updated. Every ME patient should have their physical ailments investigated in the proper manner by a medical team. This illness should be treated as every other illness is treated and not fobbed off with treatments like CBT and graded exercise which don't work.</i>
<b>278</b>	Norfolk and Suffolk ME/CFS Service	<i>I was given a manual wheelchair (i rely on a wheelchair to get out of the house, and sometimes need a w/chair indoors), i cant self propel due to the nature of M.E..Why give a manual knowing i wont be able to use it? I lost enhanced mobility when things changed to PIP, so now unable to afford and electric w/chair.</i>
<b>279</b>	Essex Chronic Fatigue Service	<i>My first appointment with the ME/CFS service wasn't ideal. I wasn't allowed to bring anyone in with me and this made the appointment difficult because my brain fog makes communication difficult. I ended up crying during the consultation because I was struggling so much, and I felt humiliated. I'd gone to the appointment in the hopes of getting a formal diagnosis, but in the end I left confused and unsure of where I was going to go from here. I wouldn't recommend them, and I've never felt happier than when I was discharge from their services. I feel like they have no idea how to treat us or any illness that doesn't have a cure, really. Their only hope is to throw CBT and GET at us and hope we'll go away.</i>
<b>280</b>	Not listed	<i>Even though it was helping people my local service was closed, so I had now nowhere within 30 miles to go. I only saw them for a few sessions. They were as disappointed as I was that the trust had decided to stop funding them.</i>
<b>281</b>	York - Yorkshire Fatigue Clinic	<i>The York Fatigue Clinic was a god send to my family. My daughter actually also had POTs and this was picked up there. She has improved dramatically since using the York service.</i>
<b>282</b>	Maidstone - Kent & Medway CFS/ME Service	<i>There are no m.e/cfs centres in Kent</i>

<b>283</b>	Suffolk Specialist ME and CFS Service	<i>ME has ruined my life. The specialist nurse is lovely but it's only for an hour quarterly. My GP is lovely, but I don't feel supported or advised much on how to live this new life. Mobility aids are great but funding them is expensive. My mental health has deteriorated massively as my life has shrunk. I don't know how one can go about management. Post exertional malaise feels like a real understatement. I feel almost paralysed with fatigue. Support for my family would also be beneficial - things have changed for them also.</i>
<b>284</b>	Birmingham and Solihull CFS Service	<i>I believe CBT should not be an option as it does not help people suffering with ME. Money should be used for more research instead and finding something that works for ME sufferers.</i>
<b>285</b>	Not listed	<i>Cbt helped me come to terms with having M.E. I'm not sure it helped with much else. Maple therapy clinic in St Albans helped me learn how to pace and do mindfulness. After that I've basically been left to my own devices. G.P's dont really know enough info and I dont go to them very much at all. You never seem to get the same gp twice and I dont think they actually care about long term chronic illness. I'm on loads of medication and then its basically, see you later!</i>
<b>286</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	<i>Current services are not fit for purpose.</i>
<b>287</b>	Bristol CFS/ME Service for Adults	<i>I agreed with the staff member I saw not to undertake GET because I knew it would not help me. I knew from personal experience, having already been ill 6 years, that increasing my walking meant I had less energy for other things e.g. school runs, doing the washing, feeding my kids. It was always a case of robbing Peter to pay Paul. It concerns me that if I had not know this already that I might have tried to follow a GET program which would have been detrimental to me. I am always living with a ceiling level of activity that limits what I can do. How high or low that ceiling is does fluctuate. There is no pushing through it, at least not without serious adverse effects in the form of PEM and what seems, in my case, to be permanent relapse.</i>

<b>288</b>	Middlesborough - South Tees CFS/ME Service	<i>I have been unwell for 8 years - the emphasis on treatment was to achieve full recovery and I expected this to happen within 1-3 years. I have researched ME/CFS extensively and followed all recommended treatments and yet I continue to experience the same restrictions and difficulties as at day one. I was not prepared for the possibility that this could be a life long illness or that not everyone recovers. As such I feel somewhat responsible for my lack of recovery in addition to which the stigma attached to ME/CFS means that I find it difficult to be open about my illness. I lost my job on the grounds of ill health and find the whole benefit system confusing, degrading and not fit to accommodate fluctuating illnesses. Prior to my employment ending I reduced my working hours to support my recovery and now receive an occupational pension based on my reduced hours - If i had received more information regarding the possibility of not recovering I would have taken into account the financial implications of reducing my hours. I would have also accepted the end of my employment sooner whereas continuing to work in a demanding nursing role had a detrimental effect on my cognitive abilities from which I have yet to to experience any improvement. Treatment should be based on achieving the best possible result for each individual with awareness of both best and worst case scenarios.</i>
<b>289</b>	Maidstone - Kent & Medway CFS/ME Service	<i>This only deals with activity management, not measures to address the illness.</i>
<b>290</b>	Private clinic	<i>Definitely need more help and understanding from NHS</i>
<b>291</b>	Stockport CFS/ME Service	<i>ME may cause some de conditioning but it is definitely NOT caused by deconditioning.</i>
<b>292</b>	Not listed	<i>Gut health and diet should be discussed.</i>
<b>293</b>	Middlesborough - South Tees CFS/ME Service	<i>I had CBT provided by my employer which gave me the mechanism to get back to work part time, but it felt like brain-washing at the time.  Before attending any clinic my GP put me on a PACE course at the physiotherapy dept which initially helped, but didn't recognise when I was trying to do too much and made things worse than y best.</i>
<b>294</b>	Private clinic	<i>Yes for the dwp to understand what we go through with cfs and how it affects us even though we look well</i>
<b>295</b>	Stockport CFS/ME Service	<i>GOOD ME/CFS services need to be better funded and need to be given more flexibility on how to treat patients. The 6-8 session limit is ridiculous for lifelong/chronic conditions, and it should be up to the patient and nurse to decide when the patient is no longer benefiting from regular treatment. Furthermore, the sessions should be spaced out appropriate to the patient's individual case - e.g. not always once a week, but perhaps once every few months, as adapting to CFS/ME treatment techniques can be a very slow and lengthy process.</i>

<b>296</b>	Bristol CFS/ME Service for Adults	<i>GPs need more training/information on ME. More research into the illness as a physiological condition is needed. CBT and GET should not be mandatory; it should be recognised that these treatments can worsen the condition. The DWP should be made to acknowledge that those with long-term ME should be placed in the Support Group and not made to endure reassessments.</i>
<b>297</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>Services should prescribe medication for POTS, pain and sleep disturbance. Physiotherapy should focus on helping pain and stiffness in specific body areas, using massage and acupuncture.</i>
<b>298</b>	Not listed	<i>I attended a clinic at Coppets Wood Hospital London, the only advice I was given was to meditate which was actually very useful</i>
<b>299</b>	Not listed	<i>We have 4 close family members diagnosed with ME and ALL of us have been advised to increase activity despite a worsening of symptoms. 'Specialists' quite simply do not understand the illness and, from our experience, ME is too often treated as a psychological illness. People with ME are being harmed due to not enough research and understanding of this dreadful illness.</i>
<b>300</b>	Bristol CFS/ME Service for Adults	<i>I have spent most of a decade being seriously ill with no help whatsoever, financially also! Recent privately accessed blood tests have revealed serious impurities in my system which were not even considered or looked for by the so called healthcare professionals!</i>
<b>301</b>	Not listed	<i>I was only at a clinic to get diagnosed and then i was just left to get in with it on my own with no help or advice from anyone, I got no support either from my GP and was made to feel as if I was making things up. I feel totally let down by the NICE guidelines and refused to go to CBT. I've been living with ME for more than 6yrs and although I have gotten slightly better over the last year I am still suffering and have to manage my activities.</i>
<b>302</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>As all sufferers know the only real source of advice is from Me CFS forums. The so called experts know so little and offer No help at all . They have very little knowledge as no funding to address this disease is undertaken. If you get severe there is no help no guidance and no hope. You are now the living dead. With no voice no future no life. If I could take myself to end my life at dignitas I would. They only hope is in the Hands of scientists in USA who are trying to actually sort this disease out. They too are struggling due to lack of funding because this disease is misunderstood and devastating without showing itself to the media.</i>

<b>303</b>	Private clinic	<i>Living with ME has been very difficult, medical professionals assume that you are just lazy and making things up for attention. I absolutely hate going to the doctors and being in a hospital causes me anxiety and stress. I have not received ongoing support or treatment by a medical professional that understands the illness, and have to face different doctors and explain my condition every time. When you mention ME they stop listening and any new symptoms are ignored and simply put down to the ME. I have multiple diagnosis' and have received very little support from any area, but to be able to see the same medical practitioner would help maintain some continuity of care especially at GP level. My medical notes are packed with different opinions from a large number of medical professionals, but they say almost nothing about the way in which I am affected on a daily basis because the barest details are added about each visit. Not one medical professional that I have seen in 26 years has looked at the full extent of my condition over a period of time that would give them any insight into how it affects me on a daily basis, which has impacted on my physical and mental health</i>
<b>304</b>	Bristol CFS/ME Service for Adults	<i>Need to look at everything. I was later diagnosed with POTS as well and since having beta blockers have been able to increase activity. Also suspect I have Pathological Demand Avoidance. Constant fight or flight response adds to ME. Knowing myself better has helped me to manage triggers. So many things are probably involved in ME, and it's stubbornness to improve that full investigations of all possible contributive factors should be looked at.</i>
<b>305</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>Pacing works well on paper but when you really need to decrease activities further than the basics, and are doing life alone, it becomes impossible to pace effectively. Therefore one is constantly extending oneself beyond available energy levels. More needs to be done to support people living alone with no carer to live a productive life.</i>
<b>306</b>	Leicester CFS Service	<i>From 2003 I was not monitored by anyone for many years and was told I had CFS. The boom and bust was dreadful with many blackouts. In 2009 I first got told it's ME but no support or help on how to manage it, my life or symptoms.</i>
<b>307</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>Although CBT can help in managing CFS symptoms it is not a cure and GET is very unhelpful if not damaging. I am now attending a private clinic who have found I am SEVERELY lacking in many basic minerals eg magnesium and vit B among others and the supplements I take are really helpful. Can NICE look into this approach as a way of helping people with cfs?</i>

<b>308</b>	Not listed	<p><i>There is no point increasing exercise until you are at a good base level or you will keep relapsing. ...Which may mean rest and nutritional input for a period of months. THEN start building. When under NHS care I would build up too quickly and crash - until I followed this regime. This is where psychology comes in - learning how to pace and what the patterns that caused your initial crash was.</i></p> <p><i>I feel you CANNOT get better and sustain it without blood/medical testing and corresponding nutritional/supplimentation advice. Psychological input and PET follow on from this.</i></p> <p><i>If I had continued just with the NHS CBT and PET I would not have got better. Nutrition is ESSENTIAL.</i></p> <p><i>I was personal friends with a highly respected NHS consultant who thought the condition was incurable in 99% of cases and who controlled a lot of research and funding and who doggedly refuted the value of nutrition/supplementation and adhered to a very rigid CBT model.</i></p> <p><i>My experience is that a combination of the three inputs is essential.</i></p> <p><i>Thank you for listening!</i></p>
<b>309</b>	Not listed	<p><i>The way ME/CFS is not understood by NHS health care professionals from all departments is incredulous in this day and age, all they need to know is that if you exert yourself, mentally or physically beyond a limited point (energy deficit), a relapse will occur that can shut a person down for days, weeks or more, that someone with ME/CFS has problems with creating energy from food like normal people, something has seriously gone wrong with the bodily functions, brain, nervous system, muscles, in fact most bodily functions that a normal person takes for granted, the usual response is everybody gets tired, but this is not tiredness it is full blown fatigue where you struggle to do anything most days.</i></p>
<b>310</b>	Norfolk and Suffolk ME/CFS Service	<p><i>The advice given re doing daily activities and rest has changed for each appointment. It is confusing not to understand the best way forward. Any activity worsens my symptoms. I still do not know how to pace effectively. I also have Fibromyalgia (diagnosed 2011). Advice there was to build up exercise. Kept failing. My ME diagnosis in 2018 explained why. Initial specialist did say have to advise GET even though that may not be the right treatment!</i></p>
<b>311</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<p><i>I have had ME for 25 years. I have been treated in many instances as an idiot despite a creditable post-graduate education. Having recently seen my doctors records under a GDPR inquiry, I was shocked at the inconsistencies and negative comments that have been made over the years. It is shocking to consider now that the symptoms I expressed then, and which were so disparagingly equated with a stress condition, are the same symptoms in the USA which are now synonymous with the condition known as ME.</i></p>

<b>312</b>	Birmingham and Solihull CFS Service	<i>Please, please take into account all the current international research which shows that ME isn't the same as CFS; that to continue to use the term CFS for people like myself who have well defined post exertional malaise (PEM) a clear indication for ME is completely wrong, we don't say that people who have head pain from a brain tumour have 'just chronic headache syndrome' and; to stop CBT and GET being the only prescribed 'treatment' for a serious, neurological illness and treating those of us with this awful, awful illness as malingerers and that we'd all be ok if only we'd change our mindset about it being a 'real' illness and stopped being scared of exercise!!!!</i>
<b>313</b>	Nuneaton - Warwickshire CFS Service	<i>PACE and GET create a mindset of mutual distrust between patient and healthcare professionals. The research supporting it was deeply flawed and broke with ethical standards on a number of levels. It is government sponsored malpractice for it to continue. I hope every single one of the 30 million sufferers worldwide are on your conscience every single day. Shame on NICE. Shame on Lancet.</i>
<b>314</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>I wish I'd known how severe ME can get when I was first diagnosed, and to rest then. But society pressured me to keep working and pushing myself, and the CFS/ME nurse kept saying it was important I kept doing what I could, rather than impressing on me the need to really rest so it didn't get worse. And then it did get massively worse because I kept doing 110% of what I was capable of for many years. This is not helped by the benefits system. If mild ME actually fitted the criteria for ESA/PIP, then I would have been able to rest earlier and not get so bad, but I had to keep working as I didn't fit the criteria, and then it took appeals to get those benefits even when I had become almost completely housebound. So it's not just the NHS services actually impressing on people how serious it is and the importance of rest and not pushing yourself, but until the government benefits catch up, this will be impossible for all but the richest to carry out.</i>
<b>315</b>	Preston - Lancashire CFS/ME Service	<i>Level of knowledge about ME from health practitioners in this country is shameful. You are still actively stigmatising patients and gas-lighting them.</i>

<p><b>316</b></p>	<p>London - King's College London and South London &amp; Maudsley Persistent Physical Symptoms Research and Treatment Unit</p>	<p><i>The CBT and keeping tables and plans of activity were absolutely useless and it fact upsetting and stress-inducing, so I gave up, only carrying on to maintain administrative contact with services - as this was actually the best therapeutic help they could provide to give legitimate credence with benefits, housing etc that I was clearly ill. I experienced better understanding of my physiology, symptoms, and improvement and management as a result from learning from outside sources, such as Chinese medicine. Prescribed medication made me worse; but herbs, without the toxic separation from the whole plant of active constituents dominant in Western thinking, have been far more relieving. To summarise, I am appalled that after so many years, a culture of wilful, arrogant obstruction and wholesale shoddy ignorance - as bad as if you were looking back at blood-letting, and performing operations without antiseptics from the old days - is presented as all the mainstream medical profession can offer on an illness that has devastated and disabled my life. You cannot force patients into graded exercise therapy on an illness where you do not know the cause unless it came from an arrogance where the underlying - and wholly unscientifically proven - belief, is that the illness is psychological, and therefore everyone else has to submit to what is only an idea, not a proven hypothesis. It has wasted thousands of people's precious time - of both sufferers and health care professionals - in trying to understand what is going on.</i></p>
<p><b>317</b></p>	<p>Essex Chronic Fatigue Service</p>	<p><i>Any patient support should be constructed around those who have experienced M.E. It's a very alien feeling having M.E and is super complex. The myriad of symptoms which wax and wane and can be different from one day to the next mean that the only "experts" in the field are those of us who have had a long experience with trial and error learning what works and what doesn't. Movement is essential. But activity is not necessarily the right pathway for all. Looking at the food we are eating and anything in or environment that is making the inflammatory symptoms worse is much more helpful than CBT. CBT implies that you're just getting over anxious and this can be overcome by addressing your thoughts. M.E makes you're body stressed. It is not in our heads. And so implying that it is makes your more stressed as you feel so misunderstood. A bit like when women in the Victorian era were diagnosed with Hysteria! There is some wonderful new research coming from OpenMedf and Stanford University on the pathology of M.E and also treatments. That would be a better investment of time and money. Look at their collaborative research and take the lead together with them. Thank you.</i></p>
<p><b>318</b></p>	<p>Leeds and West Yorkshire CFS/ME Service</p>	<p><i>I was told I was 'too emotional' for CBT and that my ME was caused by depression because I cried in a session when talking about missing out on fun with my children. More emotional support is needed for people coping with ME because it can be isolating, lonely and depressing.</i></p>

<b>319</b>	Norfolk and Suffolk ME/CFS Service	<i>pacing until stable then increase was the approach recommended but this did not really help me. there was no day to day support to manage this and it is very hard to manage energy levels alone. I was also told "off the record we are seeing lots of success with the Lightning Process". This process was the opposite of what they proposed with pacing. This was confusing to say the least and unhelpful and damaging to me on every level. When I became severely ill I was pretty much ignored and I felt like a failure or that had I implemented CBT or something else correctly I would not have got worse. There was no support from specialists after I became severely ill. I now live in a care home and have had severe ME for 20 years.</i>
<b>320</b>	Stockport CFS/ME Service	<i>Doctors gp's need to be taught more about cfs/m.e. my doctors do not believe in it, I no longer get help, I am too exhausted to fight doctors any more.</i>
<b>321</b>	Grantham - Lincolnshire CFS/ME Service	<i>Felt like I was back at school .I think helping to show people how to carry on with this illness instead of the stuff that went completely over my head</i>
<b>322</b>	Not listed	<i>I have been without any NHS support for many years, nothing available.</i>
<b>323</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<i>I was never given time to find my proper base level before being encouraged to increase my activity levels. It is impossible to know where to go if you don't know where you're starting from! Tbh, just filling out the record sheets was too much of a stress. I was also encouraged to abandon the way I had been resting (quite successfully) for 10 years and try mindfulness and shorter rest periods, which actually both made me much much worse. I was eventually discharged before completing the programme because I became too ill. I moved from moderate to severe and basically felt abandoned with no support, apart from my fantastic GP. Unless there is some drastic change in attitude from the establishment, no just treatments available, I feel that I have no where to go. This is quite a frightening prospect.</i>
<b>324</b>	Stockport CFS/ME Service	<i>Simply by attending the ME clinic on a weekly basis, caused me to slowly become worse and worse until now mostly housebound and often bedbound.</i>
<b>325</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>There is a huge range of advice depending on who you are lucky enough to see at the clinic, I saw a Rheumatologist who had a good grasp of M.E but I have a friend who saw psychiatrist who was told she was probably depressed. The services need well trained people who actually believe that it is a real illness.</i>
<b>326</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	<i>I was diagnosed with me/cfs by the Wigan clinic but this was later found to be incorrect. I was then privately diagnosed with Lyme disease and after treatment am now better. I lived with the me diagnosis for over 3 years which could have been prevented if I had been correctly diagnosed by the NHS.</i>
<b>327</b>	Plymouth Sentinel CFS/ME Service	<i>My specialist does home visits as I'm housebound and she is amazing</i>

<b>328</b>	Not listed	<i>The key advice I was given was to listen to my body and act accordingly. It was good advice</i>
<b>329</b>	Leeds and West Yorkshire CFS/ME Service	<i>The only advice I received under the NHS was about 14 years ago. The best advice I was given was to stop BEFORE I got tired, and to have a quiet rest day before and after doing something demanding. I tried an early version of graded exercise but found it impossible to follow without becoming worse. I was discharged despite still being unwell. I have had years of private treatment which has helped considerably (Perrin treatment) and have worked out a regime of supplements and diet controls which has also made a difference. The NHS has sadly done NOTHING to support me in the last 10 years. I feel that being labelled as an ME patient has also meant my back injuries were not taken seriously by my GP.</i>
<b>330</b>	Liverpool CFS/ME Management Services	<i>Just wish there were drugs to help, or that Healthcare professionals knew more</i>
<b>331</b>	Leeds and West Yorkshire CFS/ME Service	<i>Empathy and patience from a health professional is key in helping ME/CFS suffers improve in managing their symptoms. Also as I found being creative helped my mental health, this is another avenue the health institutions can implement as a form of social prescribing. I am more than happy to be contacted for more info at [redacted].</i>
<b>332</b>	Private clinic	<i>Thank you for finally updating NICE NHS Guidelines and Pathways as your Clinicians and Patients need you.</i>

<b>333</b>	Not listed	<p><i>I have a new GP now who has been wonderful and takes the time to read through my materials and support my private clinic. But the course was provided was a waste of my time and NHS resource. Each me/cfs patient has such a different experience, and general courses do not work because what might work done one will cause a huge amount of damage for another. I do however feel the group aspect for a support group was quite valuable but I think the number should be 3-4 max, and split by severity, and not the 9 I had as it was just too varied a group. I strongly believe (and am starting to see results) that a medical, nutritional and psychological approach needs to be taken. These existing courses focus far too much on psychological which is great, but they are not tailored and therefore end up being common sense and a nice "pep talk" but have no real value for the individual. No actual tools were taught (e.g. EFT and STOP process which I have found invaluable from my private clinic), rather being told to "change thoughts" which doesn't really work. The medical side seems to be foregone but in my experience the psychological side cannot be addressed if some of the physical isn't. For example meditation is nearly impossible if you have high anxiety, positive thinking impossible if you can't sleep, energy recovery impossible if you have deep rooted and/or unidentified viruses or infections. In many cases medication is required to bring a person down to a level they can actually apply or even understand the psychology aspect. GP's are often not equipped (or willing to be equipped) with the info and tools to support the medical side and I therefore think a consultant should be involved. Nutrition is also understated and on my course I for sure was more informed than the practitioner. I believe partnering with clinics such as The Optimal Health Clinic would save the NHS a lot of resource in the future. When I started the course I was still working fulltime, albeit remotely, but three weeks in and following the guidelines I had worst crash which continued to deteriorate. By end of course I was unable to work at all, banned from driving and diagnosed with POTS and other potential energy related heart conditions. I am in private care now still trying to get back to where I was before the NHS course. Intentions were good but the course was just not helpful at all and I wish I could go back and undo my attendance.</i></p>
<b>334</b>	Leeds and West Yorkshire CFS/ME Service	<p><i>I would like to have a GP who has an understanding of my condition. I would also like it recognised that M.E is no more a psychological illness than say diabetes is.</i></p>
<b>335</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<p><i>CBT was useful only for coping with feelings of helplessness, depression and isolation that comes with having chronic illness, not with the illness itself</i></p>

<b>336</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	<p><i>Physio should be provided - but proper hands on therapeutic massage, manipulation, acupuncture, use of TENS machines and lymph drainage. Help with adaptations to where you live. Help with getting the required evidence to apply for benefits and blue badge. Opportunity to talk - because ME isn't all in your head but it certainly messes your head up! Help in understanding fatigue. Fatigue has never been properly explained to me and it has taken years for me to recognise it.</i></p> <p><i>I have NEVER been properly diagnosed. I might have ME or I might have something else. I can't find a healthcare practitioner that cares either way. ME is a handy label for lazy healthcare practitioners when they can't be bothered to figure out if it's ME or something else. An ME service should not only give practical help with managing your symptoms and situation; but also ensure that all avenues have been thoroughly explored in terms cause of symptoms. This should not close the service off to people who find they have a different diagnosis. Someone with a previous ME diagnosis that is found to have Lyme or Lupus or MS still has fatigue - but there maybe better services available to them.</i></p> <p><i>An ME service should also review a patients diagnosis from time to time. A worsening of symptoms may suggest different treatment options or that a different diagnosis should be made.</i></p>
<b>337</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<p><i>It's not the activity that is the problem but stopping?</i></p>
<b>338</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<p><i>The NICE guidelines should be rewritten with input from a broad range of sufferers as well as researchers and clinicians who are expert in the field...people like Sarah Myhill, Nigel Speight, Malcolm Hooper. My name is [redacted].. After taking ART for a year I got back into competitive age group triathlon aged 60 and became the fastest 60+ sprint distance triathlete in 2018. This after having ME for 27 years and being diagnosed by 4 or 5 expert physicians, including [professional]. I think that Judy Mikovits' work with retroviruses should be revisited as it was all fraudulently debunked. Researchers are now detecting XMRV and getting positive results using Mikovits' methods, and they can prove it is not contamination. I would be delighted to be consulted as an expert patient and I am also a BSc qualified health and fitness professional specialising in physical activity and nutrition for special populations - [redacted]. Thank you.</i></p>
<b>339</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<p><i>Everyone's experience of ME is different and unique to them. Being pushed or cajoled into doing more than you are capable of or feel you can do is detrimental to the person suffering with the condition and massively affects emotional well being.</i></p>
<b>340</b>	Harrogate CFS Service	<p><i>I don't feel that some of the questions were very relevant. It is not all about activity. Very blinkered approaches do not help. I believe that you need to look at all areas of life in order to heal</i></p>

<b>341</b>	York - Yorkshire Fatigue Clinic	<i>GP knowledge of CFS/ME and available services severely lacking and advice non existent or damaging. The support/guidance of ME/CFS services likely more successful with early intervention/when first asked for referral - not so easy after year's of battling for help. Services/support need to be joined up - battling social services detrimental to health/causes relapses and GP ignored/refused to act on recommendations from ME/CFS service each saying not their position to follow through.</i>
<b>342</b>	Liverpool CFS/ME Management Services	<i>As soon as my moderate me/cfs had become severe, I was discharged from their service and left with no care from anyone, GP included. To this day, 13 years later, I have no one to care for me, including no home visits for blood draws for my diabetes or blood pressure checks for hypertension or chest pain.</i>
<b>343</b>	Leeds and West Yorkshire CFS/ME Service	<i>Healthcare professionals need to be educated so that they understand the severity of the illness and that no matter how much we change the way we think about the illness, it is still there.</i>
<b>344</b>	Middlesborough - South Tees CFS/ME Service	<i>The pathway I followed was consultant then referral to CBT therapist. A year later I've now seen a Physio, which would have been so helpful at the start of my journey as she's told me about lots of adaptations and help I could have had (I researched and made most of these myself through trial and error). Also, my CBT therapist has left and I'm now seeing a Psychologist who is using ACT rather than CBT - it's much more suited to my needs. I am a CBT therapist though, so I already knew most of what the CBT therapist was doing.</i>
<b>345</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>Patients should never feel bad for needing support. Patient care should be managed so they don't have to get so ill before they get support. There is no help for form filling and phone calls. The demands put on patients living alone in order to get benefits and services is appalling. I was v v lucky my local CFC/m.e. Service was so knowledgeable. However my gp and local hosp were not. The local hosp consultant did not make sure I was discharged with the care I need. They should have made it clear to the o.t. Assessors that I would need care in place.</i>
<b>346</b>	Not listed	<i>Was admitted to hospital after 3 weeks of this cbt and activity program</i>
<b>347</b>	Leeds and West Yorkshire CFS/ME Service	<i>Stop treating ME/CFS as a mental illness and dismiss the CBT / GET treatment approach for the uselessness that it is. Also, do not base any treatment decisions on severely flawed research.</i>
<b>348</b>	Not listed	<i>My daughter who was diagnosed with M.E. in 2009 and was advised to pursue graded exercise therapy which did aggravate her symptoms and which made her condition worse. I hope NICE are willing to take the issues with graded exercise and PEM on board. Most people with CFS/M.E. want to recover and do as much as possible without making their illness worse. Nutrition and diet are an important part of recovery. It's important that people are listened to and that experts in the field such as Dr Myhill are able to share their knowledge and best practice that leads to some level of recovery. At present the most effective help seems to only be available privately and after years of ill health I am without the funds to pay for it. I would like to see a better service available within the NHS.</i>
<b>349</b>	Not listed	<i>My experience was over many years with different aspect of service delivery</i>

<b>350</b>	Nuneaton - Warwickshire CFS Service	<i>When I first went to my GP, they suspected post viral fatigue but couldn't diagnose chronic fatigue syndrome for a number of months. I felt the doctor treated me mostly as if I had depression putting me on antidepressants and referring me for CBT with an IAPT service. I was also encouraged to continue working although with reduced hours. In hindsight I believe it would have been better for me to have been told to take time off work completely and to rest.</i>
<b>351</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	<i>If I hadn't have exercised at the start I think my condition wouldn't have deteriorated so much.</i>
<b>352</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>Some of the questions were not applicable so we're unanswered.</i>
<b>353</b>	Edinburgh - Lothian CFS/ME Service	<i>I was fit, healthy and in the prime of my life when ME/CFS hit me. I was NOT deconditioned in any way shape or form. I did not stop pushing myself and thought exercise was the best thing to get me better. How wrong I was. I am appalled to now know that of all the many symptoms I went to my GP with (vertigo-like symptoms, dizziness, heart-rate fluctuations, low blood pressure, cognitive dysfunction, numbness in hands/feet, coldness in hands/feet, unusual pain following exertion (NOT DOMS!!!), weakness in hands/limbs, sleep problems, constant headaches) were ignored - it was only after 18 months when the fatigue finally kicked in from pushing through all of the above that I was diagnosed with 'CFS'. Fatigue was the LEAST of my worries in the beginning. I had all of the characteristics of Ramsay ME, defined as far back as 1955!!! I contracted ME after suffering a viral infection immediately following an operation requiring a general anaesthetic. Again, classic triggers of ME. This whole sorry mess needs sorted out and sufferers treated with proper and appropriate medical care.</i>
<b>354</b>	Nottingham CityCare MOSAIC Service	<i>My answers for the past few questions are not accurate. Advice on activity level varies according to various factors and is highly individual. I am able to do more in the summer months, for me there is no formula to it. I think services can better help individuals by being more patient centred, finding out what they need and what they want, rather than focusing on activity levels. Perhaps this focus on activity levels comes from a place of positively valuing work and activity and negatively judging rest. These "shoulds" have no place in the care of people with ME/CFS.</i>
<b>355</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I have had to fight to obtain OT and physio services are only for specific injuries/one issue and not for long term intervention to assist in managing daily obstacles and ensuring advice given. No advice given for bedbound patients or how to access services to assist. Also never had a risk assessment in relation to health issues when bedbound (falls, circulation, etc.). Due to NICE guidelines and my non compliance with GET I was unable to be granted my full tier pension when I medically retired. I was made to attend CBT from a generic mental health service which then caused my health to worsen to becoming house/bed bound.</i>

<b>356</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	<i>At least could we have a sharing of information with regards to M.E among medical professionals</i>
<b>357</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>As a mother I was told by Bath that it must be difficult when your daughter is making herself ill ..</i>
<b>358</b>	Preston - Lancashire CFS/ME Service	<i>Not really been on any course, or to any meeting that has actually addressed my problems. Most advice on exercise seems to be counterproductive while the illness is active. Rest is key. CBT is not harmful but not really very useful. Find the cause and the cure should be more obvious.</i>
<b>359</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	<i>I've had cfs/me for 14 years - my entire adult life. In that time I have had times where I was unable to leave the house, but also a period where I was a dance teacher and exercised multiple hours a day on average. To suggest my symptoms are due to deconditioning is misleading to the point of being insulting. I have had to learn to grieve my loss of ability, and had to completely reshape my life to fit within my health limits. No treatment offered has helped me with this, so I've had to go through this painful process alone without support. The "treatment" offered did the opposite, it made me feel like I was lazy and like my illness was my own fault. Only after quitting treatment was I able to realise I'm not lazy, turn my life around, and start a new and challenging career that fits my health needs. The so-called treatment has delayed my acceptance and processing of my illness significantly.</i>
<b>360</b>	Not listed	<i>I I attended an Endocrinology Clinic, Consultant an M.E. expert</i>
<b>361</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>Pacing would have been the most helpful advice. I was offered mindfulness but was unable to get to the clinic for more than one treatment at a time. I found online mindfulness help instead. CBT helped with one of the triggers for my M.E. but the pushing to do more exercise every week was damaging. Getting to clinics is impossible for some people with M.E. so they/we need help more locally. the journey to and from the clinic cancelled out any help they were able to offer.</i>
<b>362</b>	Essex Chronic Fatigue Service	<i>Apart from the allocated 12 sessions with an Occupational Therapist at the service, there is no ongoing support.</i>
<b>363</b>	Oxfordshire CFS/ME Service	<i>There is little joined up analysis or thinking beyond my GP. Support is non-existent and I have had to manage my own condition since I was diagnosed in 2013. Nearly seven years of little to no help.</i>

<b>364</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>I'm grateful for the support provided by the team at Sutton Hospital. I don't believe that the information they provided was down to them deliberately trying to provide incorrect information. I would also like a way that even if it's just once a year or once every two years that you can speak to someone from the clinic. As it stands there are so few people within the clinic for such a large area that they cannot keep you on their books and look after you. There is a diabetes have to be checked every few months it would be helpful if there be something for ME. Also if any new voice comes out that they can provide it to you.</i>
<b>365</b>	Salford CFS/ME Service	<i>Yes, this questionnaire is terrible. Many of the questions are ambiguous so I don't know how you can use the responses. You don't include anything about what has actually helped for me, that specialists should be learning and sharing (cutting out histamine, going Keto, drinking salted water, closely pacing my brain clarity/energy hour by hour and doing no more than that). Why are you asking about increasing activity? My capacity changes hour by hour, up/down, there's no 'increase' to be had. A lot of nonsense here, start again.</i>
<b>366</b>	Not listed	<i>The lack of understanding from all the healthcare professionals I came across had been v dispiriting</i>
<b>367</b>	Not listed	<i>I am a positive person and have never suffered with depression since becoming ill with this condition almost 9 years ago. I did not need CBT, and GET only made my symptoms significantly worse. The ONLY thing that has ever improved my symptoms was being on long term steroids for an additional illness, which indicates to me that my illness is biological in nature, not psychological. My then GP agreed with me.</i>
<b>368</b>	Nottinghamshire PICS CFS/ME Service for Adults	<i>Postcode lottery and it's not fair - moved house and currently no support here at all!!!</i>
<b>369</b>	Wells - Somerset CFS/ME Service	<i>The lack of understanding of ME made all interactions, especially 1:1 really daft, and really subjective. So, unfortunately, useless. Telling the clinic I struggled to walk and get to the appointments (just from the car park!) took a long time (another couple of appointments) for them to finally understand! They finally adapted to giving me phone appointments. It was most bizarre, I felt ignored, brushed off several times. It was so strange, felt completely like I was in the twilight zone! Their belief is clear that ME patients believe their debilitating symptoms are in their heads. It is outrageous, and worse than receiving no support at all.</i>
<b>370</b>	Bristol CFS/ME Service for Adults	<i>Was told not helpful to keep diary of symptoms and they subtly made me think I needed counselling. They also did exercises in class. You were told only do it if you can but it still makes you think you should be doing it.</i>
<b>371</b>	Bath Centre for Fatigue Services	<i>Please get rid of GET it made me worse!</i>

<b>372</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>I think the advice should really be tailored to the person. Some people have found they can keep increasing their activity levels through GET, and they have recovered, and I don't think that should be taken away from people in the future. However equally, some people can't, or can't increase past a certain point, and obviously need more treatment than is available, so the therapist should be able to recognise this and tailor accordingly.</i>
<b>373</b>	Bath Centre for Fatigue Services	<i>I felt professionals delivering the management information were far too positive! It made me feel more frustrated. I feel they should have given more time to recognising the loss this causes and giving more practical advice on managing employment etc. Also there was little info about nutrition or anything particularly medical given by the consultant who was an OT not a medical consultant. That I found difficult to take.</i>
<b>374</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The best thing about the clinic was being believed.</i>
<b>375</b>	Bishop Auckland - Durham & Darlington CFS/ME Service	No

<b>376</b>	Not listed	<p><i>The entire NICE guideline should be scrapped as not fit for purpose and potentially harmful to patients with ME. The entire biopsychosocial model should be eradicated along with CBT and GET. Myalgic Encephalomyelitis is the correct name for the disease. CFS or any other name or term should also be scrapped. Reference to the PACE trial (and any of the other similar or related trials carried out by advocates of PACE) as the gold standard for treatment should be scrapped. This should also apply to the DWP and welfare assessments etc. We need to wipe the slate clean and start again with the right and truly knowledgeable people writing the guidelines etc. True awareness of this disease needs to be brought to public, government and medical professional's attention.</i></p> <p><i>Lumping many people with many causes of their symptoms together under the term CFS (or any other name) when they don't all have the same illness is just muddying the waters and is a wastebasket non diagnosis that is not helpful to anyone.</i></p> <p><i>The medical profession has to be retrained with the latest biological research developments and current understanding and recalibrate the entire system for ME patients away from the past (and current) harmful, ignorant, unhelpful, damaging and frankly insulting, incorrect and outdated thinking. The government, DWP, NHS, NICE in the UK and the equivalent bodies around the world need to finally recognise and accept the enormity this disease, the damage and misery it causes and stop the mistreatment, misdiagnosis and dismissal, lack of care, discrimination, refusal of welfare etc. More funding needs to be put in place for biomedical research to be carried out as soon as possible.</i></p> <p><i>The NICE guidelines for ME are the point of reference for medical professionals and the first change needs to begin there.</i></p> <p><i>The 250,000+ patients in the UK with ME hope this doesn't all fall on deaf ears and is the beginning of change that we have all hoped for for many decades.</i></p>
<b>377</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<p><i>Without any directions, my ME symptoms worsened as I tried to improve my energy, thinking I could beat it. I declined to a deep level, house and bed bound now lasting over 25 years. Now also diagnosed with POTS, NMS, possible Ehlers Danlos type 3, my daughter also diagnosed with ME and being tested for POTS. Hyper mobility runs through my wider family. No doctor has the knowledge or the interest to link it all together. I knew what I was dealing with and had to insist doctors tested and confirmed diagnosis. This illness is life changing losing my career, altering how to deal with each day, no holidays routine in paramount. And still 25years on being told by a consultant there's no money, no interest, no research and a variety of negative views held by GP's.</i></p> <p><i>Never being asked how my ME is doesn't help, it's as if because they have no fix they don't want to know.</i></p>
<b>378</b>	Not listed	<p><i>The clinic advised exercise, pressured me repeatedly to take antidepressants and offered no hope or useful advice.</i></p>

<b>379</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>Patients need to be told that if they continue to exert themselves while ill especially in early stages, they may end up permanently disabled. I used to be able to walk. I was encouraged to keep going and even increase my activity by several London services. I took their advice and I now have severe M.E., am completely bedridden and can no longer stand or walk. I may never recover. This is a serious physiological disease and NOT the same as fatigue. Please change this as soon as possible so that others don't end up very ill and dependent on carers.</i>
<b>380</b>	Leeds and West Yorkshire CFS/ME Service	<i>There should be research done in the link between hormones and CFS. Mine correlate massively but there has been no research so no treatment options.</i>
<b>381</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>CBT helped me come to terms with my diagnosis and chronic illness. It helped me manage my expectations and my guilt towards my family, my friends and my work. It did however do nothing for my ME. My illness is post viral, if there would have been an instant care plan when I was first diagnosed I feel I would be in a better place now. Also there needs to be more understanding of ME across healthcare - meeting my GP or any other healthcare professional and always being the one that knows more about ME makes me feel very unsafe. I am a healthcare professional myself, I have shared my journey and supported patients in my care - they all feel the same. And they always thank me for knowing about ME as they feel they are all ignored. This needs to change and I can't do it on my own.</i>
<b>382</b>	Leeds and West Yorkshire CFS/ME Service	<i>Yes, I would like it to be compulsory to have a brain scan. I would also like recommend to rest, and have social services able to help out with this. I feel like the awareness of how to support Me/Cfs sufferers is so low amongst benefit assessors and social care services.</i>
<b>383</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>There needs to be more funding for services. Wait times for treatment are harmful.</i>

<p><b>384</b></p>	<p>Not listed</p>	<p><i>I can't answer the last question as there was no planned increase in activity.</i></p> <p><i>I asked for CBT from the CFS management clinic to help with what I thought was reactive depression but refused to attend the rest of the course - I simply was too ill to go to it without making myself worse. The CBT helped a little in that it was good to have someone to talk to but otherwise not with the emotional/cognitive problems and was so exhausting that it made my overall condition worse.</i></p> <p><i>To me, the most important person to have treating M.E. patients is a physician consultant, well informed in biomedical research, who has the authority to prescribe off label medications, vitamins, supplements etc that can help, who is seeing so many patients that he/she becomes expert in diagnosing of M.E. and differentiating it from other similar conditions such as Lyme's, M.S., Weil's, anxiety, depression etc; and who is able to give proper, helpful, advice.</i></p> <p><i>I would also like GPs to be trained properly and to be able to give the right advice - it took 25 years to get a diagnosis and not a single doctor in all that time asked me what I meant by 'tired', or how it affected my life or if I had other symptoms such as muscle pain e.g. walking up hill, dizziness standing, feeling very cold, memory problems.</i></p> <p><i>When I became quite severely ill I was given the advice to get plenty of fresh air and exercise with no qualification: I tried and got very much worse for a long time. Three decades on I am still only being offered Psychiatric run management services or Neuro consultants who believe that Chronic Fatigue (not even syndrome) and M.E. are the same thing and are somatoform illnesses.</i></p> <p><i>I am one very angry patient that has had my life ruined by this illness, made worse by ignorance and prejudice in the medical profession and has seen too many others made worse by GET and GAT.</i></p> <p><i>The Oxford Criteria has to be declared invalid as does any research based on it.</i></p> <p><i>I was initially diagnosed with PVFS but abundantly meet the International Consensus Criteria for M.E.</i></p>
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<b>385</b>	Not listed	<p>Doctors keep telling me they are not qualified so send me to consultant who sent me for pots testing ..positive ive been given no advice support or information on managing these conditions just dead ends or conflicting opinions it has been a living hell. Everything i know to manage my conditions has been through self educating and implementing dietary supplement and self adjusting pacing.</p> <p>I was told by GP that there is no me/cfs specialists no autoimmune specialist no pots help just an exercise booklet, the physio wont waist their hydrotherapy budget on fibro and chronic fatigue patients.</p> <p>I have me/cfs, pots, fibromyalgia allergy asthma and multichemical sensitivity with drug allergies post exertional malaise, tinnitus, hearing and visual disturbances.</p>
<b>386</b>	Exeter, East, Mid and North Devon CFS/ME Service	<p>ME/CFS patients need a lot more acknowledgment, support and access to treatments which may help them that they are receiving at the moment. But the most important thing is that no patients feel pressured into doing any activity/exercise that they cannot sustain, as this is incredibly harmful and can result in a huge relapse, which may not be possible to fully recover from. Thanks for listening.</p>
<b>387</b>	Norfolk and Suffolk ME/CFS Service	<p>It seems that certain services in the UK are well, well behind with giving advice and support to people with M.E.. Many seem to be woefully overburdened and this I think has a lot to do with untrained and unconfident general practitioners refusing to give advice and instead turning people over to a service that can barely cope. Empower GPs to recognise the symptoms of M.E. and to give safe advice or at the very least to signpost advice that can be immediately accessed!</p>
<b>388</b>	Oxfordshire CFS/ME Service	<p>The type of CBT on offer wasn't about managing the illness but rather 'to find out what is wrong with you' ie why you are imagining you are ill. In other words the patient is being blamed for their illness.</p>
<b>389</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	<p>I feel very let down by the NHS with regard to any supportive help in dealing with M.E/CFS. At a Pain Management Clinic, I was on a Fibromyalgia Course, as the Assessment I underwent believed that I may very well have Fibro. These illnesses have been causing many thousands of people in the Uk distress, misery and suffering for at least 25 years, and continued to spiral until the present day. This is appalling, it has been swept under the rug until it has become a crisis. If some research had been started earlier, by reducing slightly the funding continually being spent on many other illnesses that had become more understood, then patients like me and all the other thousands, past and present would at least have an accurate diagnosis, and possibly Doctors who can explain what their illness is rather than us just living fearfully with the unknown. Local Clinics, support groups and access to Complementary Therapies would make a huge difference.</p>
<b>390</b>	Not listed	<p>Clinic did their best but had little knowledge of exactly what cfs is. Consultant was not particularly communicative and I was diagnosed with very little explanation or support. Subsequent sessions at the clinic were unhelpful.</p>
<b>391</b>	Suffolk Specialist ME and CFS Service	<p>I'm sick ~ please work harder to find ways to help,/heal me. I've lost 11 years of my life ~ I want to live again. Thank you</p>

<b>392</b>	Leeds - Yorkshire Centre for Psychological Medicine inpatient care	<i>GPS need more training in CFS as most disbelieve it exists and cannot recognise and treat early signs before they become severe.</i>
<b>393</b>	Not listed	<i>I saw different GPs and they had vastly different approaches and attitudes towards CFS.</i>
<b>394</b>	Nuneaton - Warwickshire CFS Service	<i>I was not given useful advice by my gp prior to seeing the specialist and it was a 9 month waiting time to see them and 2 years to get a diagnosis</i>
<b>395</b>	Hull and East Yorkshire CFS Service	<i>Please ensure there is funding for biomedical research- not behavioural therapies that have a very limited value. Also please ensure NICE guidelines and GP training /guidance fully embrace the latest global biomedical research, particularly that which is emerging from highly respected researchers at Stanford University and their partners.</i>
<b>396</b>	Bristol CFS/ME Service for Adults	<i>This illness needs to be taken seriously by the medical profession and they need to work towards a REAL understanding of patients needs by listening to them and adapting their treatment.</i>
<b>397</b>	Essex Chronic Fatigue Service	<i>I am truly appalled to hear today similar stories to mine all these years ago and cannot understand how this is. Scotland, and Edinburgh/Lothians in particular seem to be caught in a time warp of a lack of understanding of this serious and disabling illness which has partly devastated my life. In my own GP practice whenever I mention ME (not often for obvious reasons) I am met with either a blank look or it is ignored altogether. Once I asked a direct question and the response was "oh yes there's some research now isn't there?" No enquiry as to how I was coping with ME although I have now been coping for over 30 years and apart from a few referrals in the begging to rule out other illnesses, and then the referral to the ME Clinic, absolutely no help whatsoever from any medic. I believe, as do my family and friends, that this is a gross dereliction of duty.</i>
<b>398</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>Yes. I am very grateful indeed for the support offered in Sussex. Exemplary. Many thanks indeed.</i>
<b>399</b>	Not listed	<i>When I was diagnosed with ME I was lucky to have a knowledgeable, well informed and supportive GP. Sadly he eventually retired and since that I have been told I have de conditioned my body, I'm in shtook, there's little point having hope and maybe best of all if I had thought about having a baby and did I know if having a baby could help/cure ME. The only other help offered was a course after six months of having it, that was packaged as recovery course but was actually CBT and GET. To put it bluntly this isn't remotely good enough. You can not train yourself out of ME, it's the equivalent of breaking a leg and being told just go for a run on it, that will solve all your problems!</i>

<b>400</b>	Salford CFS/ME Service	<p><i>There was an emphasis on over exertion being entirely responsible for any relapse. Little consideration for any physical cause. But on balance, the course at SR was very helpful. I would have benefited from some longer term follow up and support.</i></p> <p><i>There was also a referral for exercise therapy, it was circuits round a gym. Their philosophy was definitely about deconditioning. I politely declined! That would have made me very ill.</i></p> <p><i>I know many people are put off accessing psychological help, as they believe that implies that it's a psychological problem. It's about using psychological strategies in order to better cope with a very debilitating, multi systemic condition.</i></p>
<b>401</b>	Birmingham and Solihull CFS Service	<p><i>I wish I had been advised to rest when I first got ill. It took well over a year to get a clinic appointment.</i></p>
<b>402</b>	Not listed	<p><i>It would be SO helpful to have a single point of access. Someone I could call who would then confer with other professionals on my behalf. For example, during a 'low spell' I didn't know who to contact - Physiotherapist? GP? Pain management clinic? Also, with my impaired mental capacity it's far too easy to get overwhelmed by the number of people I have to deal with (and having to repeat my life story to).</i></p>
<b>403</b>	Not listed	<p><i>M.E. is a physical illness. Mental activity is as exhausting as physical activity and I can do very little. Trying to do more activity exhausts me. I have had severe M.E. for 29 years. I get no support at all from my GP surgery for my M.E; as at present there is no cure - but I would dearly like some support. As there is no Specialist or Consultant support offered I am penalised by the DWP for this who have taken away a lot of my benefits as I am not seeing a Consultant even though I originally was diagnosed by a Consultant years ago. Until Nice actually listens to those with M.E; rather than to trial data that has been proven false, until it recognizes this is a physical disease with severe symptoms (that cbt and increased and increased exercise does not cure) and until it actually states this, patients with M.E. will not be given the support they need - in fact the opposite.</i></p>
<b>404</b>	Not listed	<p><i>GET &amp; CBT are not treatments for ME and should not be forced upon patients. They made myself and many others worse. They are harmful. More biomedical and neurological research would be much better. Or a Psychologist who specialises in grieving your old life, adjusting to illness and who will recommend rest and prioritising health other everything else. Also many people feel their bodies are betraying them and feel guilty for not being able to do things they once could, so help with coming to terms with these rather than being shamed and blamed for a disease we have no control over</i></p>
<b>405</b>	Nuneaton - Warwickshire CFS Service	<p><i>We need more research into the cause of ME/CFS and GPs need up to date training on this condition and how to treat patients.</i></p>
<b>406</b>	Norfolk and Suffolk ME/CFS Service	<p><i>I'm fed up of being belittled by healthcare professionals that clearly have no understanding or sympathy for our condition.</i></p>

<b>407</b>	London - University College Hospitals Children and young people's specialist adolescent services	<i>The Clinic was great, but it took many months to access it, due to lack of understanding from GP and somewhat of a view of it not being 'that bad' or not real. Need more understanding at a GP level as to access the Clinics you have to go through a GP. If a GP does not take it seriously and/or has a lack of understanding and knowledge of it, then it makes it incredibly difficult for those suffering to get the help they need. The delay in accessing treatment and support can cause further deconditioning/damage and leave people suffering not only physically but mentally too. There is also a problem of lack of clinics/services available for those between 16 and 19, or for the routes to then get to a clinic. For example, those nearly 18, are likely refused by paediatric services, and may be too young or unsuitable for adult services. To have more transitory services available would be great. UCLH's clinic goes up to 19 which is definitely a great decision. I'm grateful for this survey to be done.</i>
<b>408</b>	Stockport CFS/ME Service	<i>Other areas appear to have more staff and services offered within their ME/CFS service. It would be good for my service to match this</i>
<b>409</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>I now believe that my severe ME was caused by joint instability in my cervical spine causing brain stem compression. I believe that when I went through puberty and also grew a lot and produced more collagen that this pressure reduced. Appropriate MRI of my cervical spine would have been an appropriate start.</i>
<b>410</b>	Not listed	<i>Most recent advice is being given by a Mental Health Nurse who says she has treated many people with ME. She wants me to do short exercise each day (but I already do the minimum I can do anyway on the days when I am not bedridden). She says she wants me to trust her that she knows what she is doing but she is willing to read about why GET is not good. The Welsh Assembly has agreed to continue to follow NICE guideline so still recommend CBT and GET.</i>
<b>411</b>	Sunderland - South of Tyne CFS Service	<i>Due to the clinic being part of the psychological services I felt I had no support or understanding of living with physical symptoms . There was no medical input for a physiological illness. Go to your Gp was the go to answer which is easier said than done. I had high Hope's when referred to the clinic after years of not knowing what was wrong, however my hope dissolved into a pointless waste of precious energy attending the clinic.</i>
<b>412</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<i>Despite being unwell I was discharged with no warning or preparation just before I turned 18. They did not transfer me to an adult service and gave me poor advice.</i>
<b>413</b>	Not listed	<i>Having waited 18 weeks for an nhs referral appointment and then be told you don't fit the treatment criteria is a real blow to confidence and morale. This clinic sent me away to see a psychiatrist and loose weight, as if I was not really diagnosed with CFS/ME. I have taught myself pacing from the St Barts leaflets on the Internet, and have then found a private specialist M.E. physiotherapist (who also works on the nhs in a CFS clinic). I think that the nhs services need to be standardised and that every patient should have equal access.</i>

<b>414</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>I run a support group and I have learned more about my condition from a newly qualified nutritionist who specialises in chronic illness. Learning about mitochondria, cortisol levels, adrenal, serotonin, bacteria, inflammatory foods, fats etc helps you make better lifestyle choices and have a better understanding of the illness.</i>
<b>415</b>	Essex Chronic Fatigue Service	<i>I cannot stress enough how abhorrent I found the attitudes of the staff, their treatment of me in the clinic and the unsupportable beliefs that governed them.</i>
<b>416</b>	Wigan - Wrightington, Wigan and Leigh Chronic Fatigue/Myalgic Encephalomyelitis Service	<i>More money should be put in to the services</i>
<b>417</b>	Not listed	<i>I attended Dorset Chronic Fatigue Syndrome/M.E service for children and young people.</i>
<b>418</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>I would like GPs to be more aware that CFS affects fit and active people. I would like them to advise patients with vague symptoms who they run blood tests for but get no obvious result to come back and discuss those inconclusive results. I thought that if the blood tests said I was fine, I was fine, and I was not. It was not until I became more ill and started pushing that my GP understood what was going on. My improvements during my time under the NHS clinic were nothing to do with their care and wholly to do with private treatment I accessed at great cost and from CBT offered for an unrelated issue but delivered by a fabulous practitioner. I am still gradually healing by following nutritional advice to assist (not fix) my digestion and importantly to address my autonomic nervous / lymbic system dysfunction, which I think is the root cause of the illness.</i>
<b>419</b>	Salford CFS/ME Service	<i>Just attending the clinic caused me to relapse. I have not regained my levels of 'energy' back to those I had before attending the weekly appointments.</i>
<b>420</b>	Preston - Lancashire CFS/ME Service	<i>I feel like I was let down, when I was feeling at my worst...having been admitted to hospital several times at the start of my diagnosis, having to have a failed lumbar puncture, as well as a successful one, a barrage of blood tests, scans, being told I potentially had a serious illness... and when i reached the point of seeing the ME/CFS specialist, who was lovely and apologetic, to be told it was my first and last appointment... because of the service being decommissioned... was soul-destroying. I was basically given two booklets of information, and that was it!!! There is nothing in my area at all, for support, information or anything else... and I know it is needed badly, because I know several people personally with ME/CFS...</i>
<b>421</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>Pacing, strengthening, changing throughs, all ok for management of symptoms. the core effects of constant fatigue are overwhelming. the differing underline attuned/ believes that you are some how refusing to get well.</i>

<b>422</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>The ANS rewire programme has been the most helpful thing for me so far</i>
<b>423</b>	Essex Chronic Fatigue Service	<i>CBT should not be offered as a treatment for symptoms of ME/CFS as it is a neurological and not a psychological illness. CBT should only be offered separately for co-existing mental health issues. It is oversold as a therapy - I found it only somewhat useful in dealing with anxiety. Counselling to come to terms with my grief about my disability was far more helpful for the first few years of illness. The whole concept of Graded Exercise Therapy implies that ME/CFS is psychosomatic, when there is plenty of research proving this is not the case. GET is harmful to ME/CFS patients, often causing patients to significantly deteriorate, and must be withdrawn as a treatment for ME/CFS immediately.</i>
<b>424</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>The pressure I felt to comply with treatment (GET) was subtle - I wasn't harassed into it but as I trusted the staff treating me I wanted to do my best to follow the programme even though I was clearly struggling. I was made to feel that failure to improve following this approach was down to a flaw in my personality- i.e. being too anxious and analytical- I realise now it was simply because I was too ill for GET and the struggle to succeed at it was very damaging- physically and emotionally/ psychologically. I am still severely ill 5 years later.</i>
<b>425</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	<i>Supplements, specialist equipment e.g wheelchair, and holistic/alternative treatments that I am taking on privately are expensive. The NHS system is very unbalanced for poorly patients like me.</i>
<b>426</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>Pacing is very difficult as what one can do varies on a daily basis, depending on multiple interacting factors. Constant adaption is required. It is not easy.</i>
<b>427</b>	Not listed	<i>I live in Northern Ireland, where we do not have any ME consultants or clinics under the NHS. The private consultant I attended, works in conjunction with a local ME Group, and visits Northern Ireland to see private patients. It is not right that 7000 ME sufferers in Northern Ireland should be at a disadvantage to professional help.</i>
<b>428</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<i>CBT has not cured me but enabled me to come to terms with living with ME. The care and support and guidance has been beyond helpful. If this goes, what happens then? So many people could be helped with this level of care. As long as the therapist knows and understands ME, it can only do good. CBT has such a bad press within the ME community, somehow that needs to change.</i>

429	Not listed	<i>What is most needed is inpatient diagnostic units, where patients with poorly understood signs and symptoms could be seen and researched by a diagnostic team from a wide range of specialities, until the individual cause is established and a personal treatment/cure devised. Until we have a proper Diagnostic Services, there will be no end to the suffering of the many thousands who are dumped in limbo by the NHS and the rest of society until we die.</i>
430	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	No
431	Bath Specialist Paediatric CFS/ME Treatment Service	<i>I feel there needs to be a totally new way of how ME/CFS 'treatment' is given and money needs to go into biomedical research rather than psychological.No treatment is better than bad treatment as bad treatment can have awful consequences physically and mentally on an individual already suffering and coming to terms with there illness.A child getting Anxiety from those that are suppose to help and support is just awful! I would also like to see ALL GP getting a greater understanding of ME/CFS and told it is undoubtedly a physical illness to stop this stigma.Also ALL GP given training to help and support patients including children by treating symptoms appropriately as too easy to say it ME, reassuring Patients that they are "believed and supported"</i>
432	Penrith - Cumbria Persistent Physical Symptoms Service	<i>I have felt utterly unsupported and lost with this diagnosis and any symptom management support/advice has been zero! I was only offered a place at a psychological rehabilitation group with others with ME/CFS, FND, fibromyalgia and what they termed any other 'medically unexplained symptoms!!' I needed 'treatment'.....and to understand the cause of my illness. I needed comprehensive tests to rule out any other conditions. I needed the diagnosis explained to me and did not need to be lumped in together with others with "medically unexplained illnesses!". I needed to speak with a Health Professional that understood ME/CFS and talk with me about prognosis, recovery, etc. Instead I got CBT! I was a Mental Health Nurse and I could not understand why I was sat in an 8 week psychological therapy group when I had a physical illness!</i>
433	Not listed	<i>each session lasted 3 hrs, too much for an ME patient, they did not supply me with any information I didn't already know and knew less than I did. I didn't do the 6x 3hr sessions instead went 3 times to discuss options and session details tho the only person i had the meetings with was a psychologist. Gps have offered no help or advice but tried to push antidepressants on me for a few years</i>
434	Grantham - Lincolnshire CFS/ME Service	<i>Prior to attending the course my practice nurse advised me to increase my activity level by going to the gym or swimming, at the time I could barely get myself to the pool let alone swim - this caused a major relapse in my symptoms. My main concern is that I have had no follow up at all since attending the course in 2010 and my symptoms are now much worse than they were then.</i>

<b>435</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>M.E. should also be recognised at hospitals when attending a&amp;e and clinics about other health problems. Being made to stand too long, to have to walk long distances to get to appointments and then be looked on as strange because we are struggling is humiliating</i>
<b>436</b>	Not listed	<i>Rest and diet helps the most.</i>
<b>437</b>	Not listed	<i>In addition [professional], I saw a Specialist Occupational Therapist, had a GP who was knowledgeable and worked with my consultant and I was later given CBT close to home by a lady who teaches it and was open to working with me and learning together. I had a wonderful package and it took me 12 months to recover enough to resume full time work. The knowledge I gained has been invaluable to me over the last 15 years, seeing me through periods of relapse as the service that replaced this was actually harmful to me when I was referred.</i>
<b>438</b>	Bristol CFS/ME Service for Adults	<i>Would like research into causes and treatments or cures. Would like diagnostics run. Would like support and understanding. Would like support for benefits and OT (wasn't allowed a 3Rd choice on previous question).</i>
<b>439</b>	Not listed	<i>You finally find a clinic that is actually allowed to provide medical help to ME patients, you wait six months for an appointment and you get nothing.</i>
<b>440</b>	Private clinic	<i>Some of what the clinic offers is quackery, but I'm very glad it exists.</i>
<b>441</b>	Not listed	<i>There have been many times over the years I've been managing ME/CFS when I wish I had access to some support. GPs know nothing, so can't help, but there are nowhere near enough specialists who actually understand the illness enough to provide a little support when needed across the county. A one off consultation is a blessing, but takes months to get and you wouldn't want to take up an appointment when you're struggling, but others are in far more need than yourself. Simply put, more funds are required for ME support and research.</i>
<b>442</b>	Not listed	<i>He gave me some information sheets which were mostly useful (though some of it was pretty hokey, e.g. breathing techniques) and recommended some supplements that unfortunately still weren't very helpful.</i>
<b>443</b>	Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service	<i>I thought the consultant's behaviour was atrocious, but didn't have the energy needed to complain. I just hope I was the only person he shouted at and was so rude to, just because I wanted to get better.</i>
<b>444</b>	Torquay - Torbay and South Devon CFS/ME	<i>The service ought to be able to do things like refer you directly to a neurologist. They don't currently have the clout to do that.</i>

<b>445</b>	Not listed	<i>Nobody tells you it can be progressive and can kill you. Nobody tells you that some crashes become permanent. We need melatonin and more pain and sleep meds via GP for those us housebound. Hands on physio and meds advice would be the best help. GP sees nobody else so severe. Cumbria Partnership PPS missing (renamed CFS/Fibro clinic). Scrap all psychologists - mental health system referral can be used. 3Ps model is so toxic, image asking people on first appt how they are "perpetuating" their incurable neurological disease.</i>
<b>446</b>	Essex Chronic Fatigue Service	<i>When I was assessed by the clinic I was told I had to go in on my own, there were three people in the room for the assessment. They were entirely focused on my weight and didn't listen to anything about my symptoms, they sent me away to be tested for sleep apnea, despite me telling them I didn't have it. It then took almost a year for me to be assessed by them again. They refused to let anyone in the assessment with me again, this time there were 2 people assessing me. Again they were entirely focused on my weight. After I had told them I was now struggling to walk at all, they told me the reason I couldn't do so much, is because I haven't been trying to do enough. I told them this was the opposite of my entire experience of being ill, and that actually pushing myself to try to maintain my previous level of act</i>
<b>447</b>	London - Uxbridge - Hillingdon CFS/ME Service	<i>NICE, please start taking in to account the biological aspects of the disease such as mitochondrial dysfunction and PEM.</i>
<b>448</b>	Liverpool CFS/ME Management Services	<i>Graded exercise is damaging and cbt is condescending</i>
<b>449</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>I found CBT and GET unhelpful and actually made my condition worse...one cannot talk someone out of a physical illness, and exercise causes acute exacerbations of muscle pain, muscle fatigue, general flu-like malaise, and fatigue, with increasing cumulative effects. The most helpful and appropriate management has been Pacing rest and gentle activity tailored to the severity of the illness.</i>
<b>450</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>Once I was diagnosed I have been left to my own devices. I was offered CBT, but waited 6 months for appt and by then I had been bedbound, and so I was discharged, which I think is unfair...fatigue Clinic was a great help I was diagnosed, but I was waiting for a year for an appt. And I had been ill for over 2 years and lost my job by then. It would be a great help if the clinic's offered regular appts to assess symptoms, and give patients a support network.</i>
<b>451</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>I was told to rest by the doctor, but not given any practical advice about how to achieve this. I was told 'men find it easier to follow this advice, women don't tend to', which I assume is because men can give up paid work, but women feel they can't give up housework, caring for their children etc. I think the NHS should provide more advice on accessing social care (which has been the biggest help to having the ability to try to rest, because you can't rest if that means there's no food to eat and no clean clothes to wear!) and benefits for people who can't work. I think they should, as a matter of course, help people</i>

		<i>to navigate these systems. Because they are the 'medicine' which allows people to rest / pace.</i>
<b>452</b>	Bristol CFS/ME Service for Adults	<i>I have been managing my symptoms of M.E. for forty years. During this time I have accumulated a vast knowledge base regarding this condition, and by default, it has been almost a full time occupation to keep myself functioning and in relative terms healthy. It would have helped considerably to cope with the vagaries of a debilitating condition if I had not been faced with incredulity, rudeness and hostility in many instances, including often from doctors. This situation alone over many years is extremely stressful. We, the patients, desperately need appropriate research into our condition, and a very clear public statement that our experience is all too real, with an accompanying explanation that it is not just real in a psychological sense.</i>
<b>453</b>	Fareham - South Coast Fatigue	<i>There is a massive lack of informed support throughout the medical profession. No one seems to know what to do with a child who has. CFS. We ended up searching ourselves and finding Drs and clinics and then had to fight to get referred. It's disgusting that GPs have so little knowledge and waste so much time before taking action. We had to travel to Brighton for a clinic first Of all. That was then closed. Then we had a support team in Havant which was great and the shut down. So finally found a the private clinic South Coast Fatigue and had to fight for trust funding for our daughter to attend. It shouldn't be this hard to get health care for child. I mean care as well not some weird psycho babble treatment that's is being rolled out by [professional] and her flunkies. That is a disgusting situation and a total misuse of power and funding.</i>
<b>454</b>	Bristol CFS/ME Service for Adults	<i>To have a definative test for diagnosis and suitable treatments</i>
<b>455</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>Six sessions is not enough, my condition has worsened and my Doctor doesn't know how to help.</i>
<b>456</b>	Manchester CFS/ME Service for Children and Young People	<i>Any service should be patient led as the is a complex condition with many variables to each patient</i>
<b>457</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	<i>I feel there is a serious lack of knowledge on how to treat CFS in the UK, I am aware of numerous treatment options offered in the US and wonder why we are still treated as mentally ill. I was seen by a psychologist at the CFS clinic, not a physiotherapist or medical Dr and this shows the continuing biases to this condition. I have been waiting for 5 months now to attend the 8 workshops on pacing/CBT etc, I am lucky enough that my symptoms are mild and I am able to help myself with online resources, but for those with more severe symptoms, they could easily deteriorate further whilst waiting for treatment - these deteriorations could be permanent due to a lack of care. Thank you for all the work you do.</i>

<b>458</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>My GP was dismissive after the diagnosis.</i>
<b>459</b>	Not listed	<i>don't tell me its in my head, why is there no specialist nurses as i feel isolated.</i>
<b>460</b>	Essex Chronic Fatigue Service	<i>I believe that my cbt therapist was unique in understanding my mental barriers in accepting my limitations and the tools such as a wheelchair and meditation skills to make my life easier . She went above and beyond to help me and continued to see me way beyond the recommended 6 sessions . She saw me for an entire year before she also became sick . She would have continued to work with me She felt she had nothing more to offer in terms of my acceptance of my limitations and use of disability aids . The best thing for me was being able to talk to someone that understood the effects of the illness and the limitations it causes with out being judgemental and only offering coping strategies that would help me without the pressure to continue with it if I wasn't comfortable with it . I also attended a group session for people newly diagnosed. I found this really helpful and supportive .</i>
<b>461</b>	Bolton - Bury and Bolton CFS/ME Clinic	<i>I agree that people need to do as much as they can... and a bit more... but graded activity and any association with mental health services should be stopped immediately. This is not a psychiatric nor psychological disorder. I am an OT and definitely know this is not in my head.</i>
<b>462</b>	Norfolk and Suffolk ME/CFS Service	<i>I only went to the clinic once for the diagnosis. Too many GPs do not accept my diagnosis -and therefore do not offer any advice or help, and they do not accept my word that I am hypersensitive to many medications.</i>
<b>463</b>	Salford CFS/ME Service	<i>The nurse I saw for a while was helpful regarding Pacing but other than that the clinic did not make any difference to my condition. I attended a mindfulness course for pain but as I was already practicing this it didn't make any difference.</i>
<b>464</b>	Liverpool CFS/ME Management Services	<i>The staff at Broadgreen seem aware the Nice guidelines on ME/cfs are not perfect and can be harmful, they seem to try and find the best way forward for individuals to manage their condition. I came away thankful that I at least had access to advice but felt I was just going to have to learn through trial and error to manage my health condition myself and the clinic were also still learning to understand the illness and were not fully confident the Nice guidelines where the best way to achieve recovery. I've now accepted my illness is lifelong and manage as best I can, I stay as active as possible but limit my activity to stay as stable as I can and avoid "flare ups/crashes" There's a long way to go Medically.</i>

<b>465</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>Poor sleep is the key aspect of CFS/ME which is not tackled by the specialists - they are hamstrung by the current NICE guidelines and this needs to be changed ASAP. Taking melatonin before sleep is a huge help, but NICE does not allow me to buy it on prescription. This situation is counter-intuitive. Informed advice on diet and food supplements is lacking, and it is up to patients to research and invent their own 'remedies'. In the UK alone, there are thousands of CFS/ME sufferers. I am sure a large proportion would be willing to take part in long-term clinical trials to help fill knowledge gaps and which will help us return to 'normal' lives. It needs to be taken seriously by NICE and given the funding needed for improvements to take place. Finally, many GPs and other medical staff are completely ignorant of CFS/ME. NICE needs to break this ignorance so that fellow sufferers can get the support and advice they need to help recovery.</i>
<b>466</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<i>I am still finding it very difficult to access appropriate services like having my diagnosis rechecked, gp assistance with getting welfare support &amp; care services. My only therapy specialists (CBT) only ever wrote unrealistic optimistic reports which has done nothing to help access services I need.</i>
<b>467</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>I struggle with help my daughter was diagnosed at 5 she is now 7 and symptoms anxiety and depression is now through the roof ,waiting for assessments half her little life</i>
<b>468</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>Caused me to distrust so-called professionals</i>
<b>469</b>	Stockport CFS/ME Service	<i>Your questions are too complex....simplify the wording is needed....help us to help you. Eg, 'When you stopped attending the clinic, how were you in comparison to when you started attending the clinic?'</i>
<b>470</b>	Not listed	<i>I suffered a relapse due to advice given</i>
<b>471</b>	Plymouth Sentinel CFS/ME Service	<i>Attendance at all sessions of this service is written into my agreement with the DWP claim for ESA. I therefore feel that I cannot provide honest feedback to the therapists of this service because this risks having an adverse effect on any report they generate about me, which may affect my relationship with my GP and negatively influence the evidence that I need to support my DWP claim. So I'm effectively holding back all the useful feedback I could give the specialist service because I need to protect my benefits claim.</i>

<b>472</b>	Wells - Somerset CFS/ME Service	<i>The emphasis is on putting up with the illness. Where is the research? Where are the treatments? Why haven't I been offered LDN or other anti- virals that have been shown to help some people? I can't afford to just stay in bed. I have not been offered any financial advice on how to cope. No wonder so many ME sufferers commit suicide.I can hardly go on.</i>
<b>473</b>	Private clinic	<i>The questioning in this survey seems designed only to test the current pacing/CBT currently advised by NICE. ME is so much more complicated. Required treatment involves diet change. Spinal alignment work, lymph flow treatment, liver support, gut overhaul, jaw alignment and EFT style support to recover from the trauma of this terrifying condition.....to re-establish hope to improve/recover. I have, indeed, recovered to a high performing level through such approach and am very happy to discuss further [redacted].</i>
<b>474</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>I was a fit and healthy woman in my 20's with successful career as a creative director, I was very happy and positive, with lots of friends, I competed in triathlons and exercised every day. As a teen I had severe glandular fever and later got the herpes simplex virus and since then have suffered short bouts of fatigue, immune and inflammation issues. When I first presented these symptoms to the gp I was diagnosed incorrectly and bizarrely with depression. All symptoms after this point were assumed to be as a result of depression. Fatigue, diarrhoea, vomiting, migraines, weight loss, swollen glands, fainting, muscle weakness etc etc, all depression. And the solution? Take stronger SSRI's. I followed the doctors advice and 6yrs on I am no longer fit for work, I can't exercise, my world has shrunk to a small group of friends and family, and the four walls of my apartment. On top of this my trust in the medical establishment is in tatters. The current gender bias in diagnosis and outdated views on ME/CSF means, that at the point when I should have been alerted that I was at risk and given simple dietary, exercise and sleep advice that would have helped prevent me developing one of the many complex diseases that can arise in the wake of these viruses and effect mostly women, instead I was put on inappropriate medication and essentially told to cheer up. I am now a drain on the NHS and the economy to which I used to contribute, and my treatment plan basically amounts to 'get used to it'. There must be a huge percentage of ME/CFS cases like mine that could have been easily prevented if views on illnesses that largely affect women were to be addressed. Whilst I am definitely in favour of a total overhaul of the current treatment program, I would also suggest that highlighting and addressing gender/racial bias in diagnosis and refocusing NHS practice and general practitioners on disease prevention rather than symptom suppression could save millions of pounds and lives. The whole process has been demoralising and degrading. The NHS wanted to label me as depressed because I was female and presenting with varied and complex symptoms, and 6yrs on and several tax pounds later they've achieved their goal, now I'm depressed!</i>
<b>475</b>	Liverpool CFS/ME Management Services	<i>Please put money into blood tests etc to find out exactly what is causing their cfs. The private clinic in london treats and people recover with correct supplements etc. The money that goes from the nhs for meds, appointments etc for life is more than if people were treated like you can if you pay £5k to go private</i>
<b>476</b>	Edinburgh - Lothian CFS/ME Service	<i>More funding from the uk government for research, and specially trained assessors for dwp benefit assessments</i>

<b>477</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I first developed ME in 1993. There was very little help available then, if there had been more help and advice then I think I would have been in better health now</i>
<b>478</b>	Newcastle - North of Tyne CFS/ME Service	<i>My diagnosis took well over a year because my first GP told me he didn't know why I had symptoms, it was "just depression" and sometimes I shouldn't expect answers and just get on with it</i>
<b>479</b>	Not listed	<i>The way that ME clinics are run, and the lack of knowledge of GPs, other consultants and the ME specialists, is disgusting and harmful. Drs are too dismissive of this condition. My own GP recently told me to catch a train to see a tertiary hospital specialist. I told her that I was unable to use public transport and would need to pay for a taxi. She insisted that the train journey would be easy and that the station was in view of the hospital. I had to tell her how much she was underestimating my disabilities. For God's sake, I'm beebound 80-90% of the time. She assumed that I could drive and go abroad on holiday too. All Drs, whether they are GPs or specialists in other fields need to be educated about ME. It is a multifaceted illness that can display more than 100 different symptoms, and it is NOT a psychological condition. Yes, depression occurs as a result of having no quality of life, no social life, no career, no family, loneliness, no help with personal care, accessing benefits...etc etc....the list is huge. I have so much more that I would like to add, but I have ME. I have to go back to sleep.</i>
<b>480</b>	Hull and East Yorkshire CFS Service	<i>Cbt gets &amp; forced psychiatric appointments are dangerous 100% for Myalgic Encephalomyelitis</i>
<b>481</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>I have seen GPs, neurologists, nurses, and physiotherapists since being diagnosed last year. The sheer range and depth of ignorance about this condition across these professions was disheartening. Most had never even heard of post exertion malaise let alone anything else. Neurologists seemed convinced that the condition was psychiatric despite the overwhelming research on biomedical effects.  As a patient you rely on medical professionals to know more than you about your condition, yet I've found that I've had to teach myself and others as most professionals had no idea about it (except for the CFS service who were great). Having read the PACE trial's research paper and GET manual, my own experiences of this condition does not agree with its model of the condition. We desperately need something better to work with and help us to improve our understanding of this disease and work towards a genuine cure.</i>
<b>482</b>	Bristol CFS/ME Service for Adults	<i>I have been lucky that the service in my area is very good and they completely understood the illness. I believe that it's not the same in all areas and I think there should be a standard service nationwide (as long as it's as good as Bristol)</i>
<b>483</b>	Not listed	<i>Can't thank [professional] enough for her support through a really difficult time. Just wish I had more to show for it, it's not her fault at all that I don't.</i>

<b>484</b>	Not listed	<i>Epsom in Surrey was clinic I attended</i>
<b>485</b>	Preston - Lancashire CFS/ME Service	<i>I had been on the course about 10ys earlier but was referred back after my ME got worse. The course content hadn't changed and part way through we learned the service was closing so, as it was one to one, I was able to choose which areas we discussed. I learned nothing new and it had no effect on my physical health. However, my worsening ME had begun to take its toll on my mental health and the second healthcare professional I saw had a lot of experience of ME sufferers developing anxiety as a secondary symptom so the biggest benefit was her helping me accept that and feel less alone. There wasn't time to come up with any strategies. She was brilliant, though, and it was a great loss when she was transferred to work with a different illness as the service closed. The first person I saw, however, had been so bad I had asked to be moved to a different centre to avoid her (I was too exhausted to put in a formal complaint). She used phrases like "yes, a lot of people with ME think they've got IBS" as though she didn't believe us. The worst time was when she emailed wanting to rearrange my appointment on the actual morning of an afternoon appointment and I couldn't get hold of her to find out more details. When I told her, later during the appointment, how difficult it would have been for me due to scheduling my rest and rearranging my lift (I need carer for transport) she blamed it all on my anxiety diagnosis. She clearly had no idea what it's like to live with ME day to day. When I said it was an ME issue, not an anxiety issue, she said "I'm not buying it. Let's move on!" So not only did she not take on board patient report of their symptoms, she also believed if it was about anxiety then it was nothing to do with her. No understanding of mental health impact of living with a chronic illness. This is why we need healthcare professionals who understand ME and what it's like to live with it.</i>
<b>486</b>	Penrith - Cumbria Persistent Physical Symptoms Service	<i>Hands on treatments such as the Perrin Technique should be offered- this has helped reduce my symptoms far more than an 8 week CBT/activity management session at the NHS clinic did. Also full investigations and tests to rule out other conditions such as Lyme Disease /autoimmune conditions.</i>
<b>487</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>Support for ME patients is spread very thinly and is insufficient to meet the need.</i>
<b>488</b>	Liverpool CFS/ME Management Services	<i>There should be so much more quality biomedical research available to inform clinics. It would make a drastic difference to the experience of patients if clinicians could provide concrete answers regarding what is going on inside your body to cause symptoms, any treatments and how to recover. At present, they do not provide any hope for recovery nor do they provide any reassurance or insight into the illness.</i>
<b>489</b>	Nottinghamshire PICS CFS/ME Service for Adults	<i>I told them that I had bought a wheeled walker to help me be able to walk further. I was told by them that I should not use one as I would come to rely on it! What part of walk further did they not understand?</i>

<b>490</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>Timing of advice / treatment seems really important. I received two sessions of CBT in the past 8 years, I think the point at which you are in your illness makes a difference. The CBT I received was not about how I was causing my illness through my thoughts, it was helping me to deal with the mental issues around accepting that you have a long term illness and advice on how to manage day to day practically within any limitations I had. I didn't find the physiotherapy I had useful as it was about trying to increase activity levels and because each days energy is different, I found it frustrating that some days I could do the suggested exercises and some days not, so there is never a smooth progression upwards always forwards and backwards within a restrictive envelope in my experience</i>
<b>491</b>	Salford CFS/ME Service	<i>The clinic I attended was a minor part of the main diabetic and rheumatology clinic. It seemed like an add on, and there was no treatment offered other than CBT(which I had already had), or GET. I knew a lot more than the doctor I saw, and there was no support service for me in general, and none at all in mid Cheshire where I lived. The travel to Salford was really tiring, and not sustainable for any treatment offered even if I had felt it was useful. The M.E. physiotherapy clinic which I was advised I could attend closed just before I contacted them. M.E. Support was virtually non existent, and knowledge of the medical staff very limited!</i>
<b>492</b>	Portsmouth Chronic Fatigue Syndrome Service	<i>Nobody would choose to have this illness, a better understanding of the illness is required at all levels. Investment is needed in the Lab and not in a CBT chair. PEM is an unbearable condition to live with and brain fog makes day to day life unbearable. Everyone who is diagnosed with CFS/ME should do the activity course and get OT help as standard. Miss diagnosed ME or illnesses that are just Chronic Fatigue should not be put down down as ME.</i>
<b>493</b>	Bristol CFS/ME Service for Adults	<i>Professionals need to be aware that ME is different for every person and there needs to be so much more research done into this. I feel like I went through the course and then just had all support stopped. We had to pick if we wanted to do the group course or do something one to one which I had no idea what would help so feel all these options should be available.</i>
<b>494</b>	Grantham - Lincolnshire CFS/ME Service	<i>I have POTS as well and for that, medication and then doing very short time of gentle strengthening exercises has made the biggest difference but only after I had rested adequately and reduced my activity levels for several years until I naturally started to do a bit more as I felt a bit more able to do. Pushing myself to do more when I feel unwell has always worsened my functioning but full bed rest also worsened my functioning. Advice on how to obtain a balance between these would have been very helpful and I think speeded up my recovery or not let me into several major relapses</i>
<b>495</b>	Private clinic	<i>The helpful clinic best to go to</i>

<p><b>496</b></p>	<p>Norfolk and Suffolk ME/CFS Service</p>	<p><i>I saw a GP with special interest in ME/CFS for a diagnosis in 2018. She was very good and made me feel so much better after 20 years of my own GPs saying it was all in my head( and I had to fight to be referred to the service). The process of being taken seriously improved my sense of well-being and hope of recovery. The OT who then took over in clinic is (I'm still going) very knowledgeable and supportive, but she admits she would like to see me more frequently than every 3 months (perhaps every month). I find it hard to stick to pacing/resting recommendations during the time between appointments and would make better progress with monthly appointments and more advice on practical/psychological aspects of managing activity.</i></p> <p><i>I would also benefit from some physiotherapy/osteopathy to alleviate symptoms of back neck and muscular pain. Having had early stage breast cancer 4 years ago (I've had ME for over 20years) the contrast between the offers of orthodox, alternative and complimentary therapies after breast surgery and after ME/CFS diagnosis were shocking. The support for ME/CFS patients is cursory by comparison.</i></p> <p><i>I cannot help wondering if I had had better treatment/support for the ME/CFS back in 1997 when I first had a PVF diagnosis and hypothyroidism, my general and immune health would have been better and therefore I may not have got the breast cancer.</i></p> <p><i>Since PVF/CFS in 1996/7 I was made to feel ashamed of having the illness and not taken seriously. I prefer not to go to the GP concerning CFS but do my own research and try to get better on my own. Going to the clinic has not given me any new information because I have read so widely around the subject. What it does give me is contact with someone who understands and is able to offer a tiny bit of support.</i></p> <p><i>Filling in this survey has made me realise how isolated I have become. I have suffered for years in silent despair. My husband and children do their best to support me,so I'm very lucky in that respect, but it is very hard for them as well .</i></p> <p><i>Please give us some more help .</i></p> <p><i>Recovery is possible with a variety of approaches and proper support: Meditation/relaxation and ways to calm the autonomic nervous system, dietary advice, massage/osteopathy, someone to talk to, a knowledgeable consultant/nurse/OT, not GET, pacing/resting help. There is plentiful research to show that support from an attentive, knowledgeable sympathetic caregiver/professional leads to improved health outcomes.</i></p> <p><i>My father and 2 uncles were GPs and/or Profs of medicine in 1950s to 1990s and were trained in detailed observation and detection of underlying causes. One was prof of pharmacology and then head of the medical faculty at Leeds University, one was prof of paediatrics at Bart's and my father a registrar at Radcliffe infirmary Oxford before becoming a GP. Unfortunately they are no longer here for me to ask for help.</i></p> <p><i>What's gone wrong with the system? I feel greatly let down.</i></p> <p><i>Thank you!</i></p>
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<b>497</b>	Essex Chronic Fatigue Service	<i>Not all choices of answers here are applicable so I've put yes where I would prefer to put 'somewhat' or 'mostly'. I also found some questions difficult to understand so my answers may not be 100% accurate. Overall I found the people involved in my M.E. healthcare and clinics in Essex to be supportive and understanding mostly. Advice has been good although it helps I've done a lot of research to choose what advice I take base on my own symptoms. My GP has been brilliant.</i>
<b>498</b>	York - Yorkshire Fatigue Clinic	<i>Please keep [professionals York] clinic running ! Highly recommend</i>
<b>499</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Total and utter lack of support and understanding for Children with severe ME</i>
<b>500</b>	Salford CFS/ME Service	<i>Salford Royal where I attended just didn't have the resources to give me what they said I should have. I attended 2 sessions of Aqua exercise (in their warm pool) &amp; was told I needed weekly sessions but then they couldn't fit me in for at least a month at a time which I was told was then pointless &amp; so I stopped going! I also found the CBT group sessions to be very depressing &amp; actually came out feeling worse than when I went in. The circuit training sessions were pointless &amp; the physio couldn't really offer me anything except to increase my activity levels each week. I gave up my sessions as I felt other patients could probably use his time more wisely than what I could. The consultant I met had nothing to add to anything I hadn't already read myself &amp; so I now manage my own illness!</i>
<b>501</b>	Preston - Lancashire CFS/ME Service	<i>I only ask that we are taken seriously. We don't ask nor want this illness but we are still being ignored and made to feel like we are faking it. We should be believed as a million people can't be lying and if it was all psychosomatic how come we all experience the same symptoms!!!!</i>
<b>502</b>	Leicester CFS Service	<i>The therapist lied about ME, saying "it has no physical component". There was no hope of any improvement given this stupidity. GPs refused to provide any meaningful treatment, even though B12 injections helped, because everything is poisoned by PACE, including NICE guidelines. I have not seen a GP for two years because the last visit was confrontational and distressing. I am mostly housebound, struggle to feed myself, cannot cope with basic cleaning etc., yet receive zero help. The PACE trial should be subject to a public enquiry in order to show how its "results" were massaged to create a misleading conclusion, and to change attitudes both in medical professionals and the public at large. Too many people have suffered too much for far too long because of it.</i>
<b>503</b>	Not listed	<i>The NICE guidelines need to remove any hint to push oneself either physically or mentally to 'get over it'. Such are most likely to produce worsening symptoms and an overall lower level of functioning. Most of the people I know with ME are 'driven' and active people prior to their illness, and it is hard to adapt, and not allow that driven self to take over - the NICE guidelines at present feed that drive which likely brought on or hastened the illness in the first place.</i>

<b>504</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>For everyone to have a better understanding of the condition and how it affects people. For the condition to be taken more seriously not 'just tired all the time'. For more support to be given to people and to recognise it affects people every day.</i>
<b>505</b>	Maidstone - Kent & Medway CFS/ME Service	<i>Since being signed off by the clinic in 2013 I have had no one see me regarding my CFS. Some GPs don't understand it, I've been told to do more, which makes me worse to read a book &amp; go for a walk. But I now finally know how much to do &amp; when I need rest.</i>
<b>506</b>	Not listed	<i>I did not go to specialised cfs clinic but attended a course set up for my area. I had very little support. I felt like I was making it up. Most of the time I have no input and have to self manage medication. Doctors need to be trained.</i>
<b>507</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>The CBT and GET process is completely out of order. It's as bad as prescribing a diabetic sugar and MUST STOP IMMEDIATELY. The DWP process of awarding benefits via assessments is appalling, the stress of going through such a prolonged process should be looked at IMMEDIATELY AND CHANGED. The whole process does nothing but add debilitating levels of stress that exasperates ME symptoms.</i>
<b>508</b>	Not listed	<i>Please change the current guidelines, they are causing harm.</i>
<b>509</b>	Birmingham and Solihull CFS Service	<i>If you are severe, it is very difficult to access any help. You just fall between the cracks unless you have someone to talk on your behalf. The people who require the most help in practice get the least!</i>
<b>510</b>	Not listed	<i>The clinic had no understanding of severe ME. Their approach was incredibly rigid.</i>
<b>511</b>	Stockport CFS/ME Service	<i>More research and funding is needed. I have had to facilitate most of my care and be at the centre of it to make anything happen. I have had to pay for counselling, CBT and dietician intervention privately as either they couldn't be offered or the waiting list prohibited this. Most of my understanding of the condition and the sciences behind it linked to ANS dysfunction I have had to do myself.</i>
<b>512</b>	Stevenage - East and North Hertfordshire NHS Trust Chronic Fatigue Syndrome Service for Children and Young People	<i>The clinic is a self managing clinic &amp; most people with ME/CFS are aware to self manage, we attend clinic for further help, beyond self management. There are currently no services in Hertfordshire that help manage symptoms &amp; help</i>
<b>513</b>	Brighton - Sussex Paediatric CFS/ME Service	<i>I saw an Occupational Therapist (Sussex ME) who could only offer CBT and GET (Graded Exercise Therapy) and couldn't provide the physiotherapy and dietary advice I requested. I was advised to 'check out the internet' for further help. I abandoned GET after three miserable weeks and felt much better for it.</i>

<b>514</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	<i>Like many I feel let down that something has not been done about this illness. For too long it was dismissed as a mental health issue which was ludicrous. There are plenty of studies that prove it to be a physical illness so it is about time money was spent accordingly to help find a cure or at least something which will help to soften the symptoms. The general public also need to be educated about the illness correctly as the stigma around it is toxic.</i>
<b>515</b>	York - Yorkshire Fatigue Clinic	<i>I would like more inclusion of holistic elements of treatment e.g. psychology - looking at mindset and approach that maintains patterns of helping others above self / specialist diet advice like paleo ketogenic diet advice.</i>
<b>516</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>In Cornwall their is effectively no CFS/ME service, Their is a pt consultant and a OT. That's it nothing else. You just have to research for yourself and hope for the best</i>
<b>517</b>	Liverpool CFS/ME Management Services	<i>Services need funding properly. GPS need better knowledge on how to support us with symptom management. I don't want CBT to help me accept that things are hard. I want help so it's not so hard.</i>
<b>518</b>	Leeds and West Yorkshire CFS/ME Service	<i>Please give us some proper help. Thousands of lives have been ruined</i>
<b>519</b>	Stockport CFS/ME Service	<i>GP's need much more training on me/cfs as I had to go private to get a diagnosis due to my own gp Ignoring all my symptoms</i>
<b>520</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>[Professional] at the royal free was so rude and judgemental i had to walk out of the consultation so did not go back as i could see she was ignorant or in denial about her useless dangerous ideas of what me/cfs is.</i>
<b>521</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>The question "Which option best describes the advice your were given on activity management?" does not have enough possible answers. I was given advice on pacing - doing as much as I could that wouldn't cause a crash on subsequent days, and finding a way to reduce activity levels on bad days, but not assuming that it would have to be reduced to zero. In other words try to even out the peaks and troughs of a boom and bust cycle. I thought this was good advice which I have followed to some extent ever since.</i>
<b>522</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>There is not enough awareness with GPs/consultants on how complex the illness is and how many different systems within the body it affects, therefore there is no real way of being able to manage the ever changing and worsening symptoms which is frightening. There are no follow ups so deterioration is not monitored and you are essentially sent home to die very slowly with no support. GpS are also very insulting and disrespectful as most believe it does not exist. Failed at all angles.</i>

523	Birmingham and Solihull CFS Service	<p>We need symptom management &amp; pain management tailored medically to each individual. CBT should be an option for people who want it, but not the "treatment". I spoke to my current GP about being referred to the nearest CFS clinic to where I am now (I'm on the Wirral, but the clinic is in Liverpool). All they do is diagnose &amp; put patients through CBT. This doesn't work. It isn't good enough. It doesn't help me manage my illness. I have always been a positive person &amp; have been told that I manage really well despite my CFS (&amp; other chronic illnesses) &amp; even I have found that CBT is of very limited value. Pacing &amp; management of symptoms are the only things that work. While I currently have a GP who is very knowledgeable about CFS/ME, this is rare &amp; I am concerned that when I move house &amp; have to move to a GP practice, I will end up with GPs who don't get it. GPs need training &amp; there needs to be a dedicated CFS/ME service that focuses on what I have already mentioned. Part of the reason I asked to be referred was to get better pain management, but my GP told me they don't offer that. There are really supportive specialist services for so many other medical conditions, but we have none. We rely on our GPs being understanding &amp; trying various options for pain relief, often resulting in bad reactions for at least one, before we find the right option for us.</p>
524	Bath Specialist Paediatric CFS/ME Treatment Service	<p>Answering on behalf of my 14yr old son, recently diagnosed. First appointment with consultant [professional] was excellent. 2nd appt was with clinical psychologist and was awful. [Redacted] no longer trusts them and wants no part of the service.</p>
525	Exeter, East, Mid and North Devon CFS/ME Service	<p>I was pushed to say I was depressed, the consultant told my gp I was because I said I was unhappy sometimes. Who isn't? Doctors need to understand what is clinical depression and what is not. They feel guilty about being unable to help and so wish to force patients into a mental illness box. So I get no help dealing with my tendency to sleep for days after normal levels of activity. I was not well enough to travel to their service regularly anyway. Foreign research is ignored, appropriate investigations are not in the guidance, doctors who might offer help cant for fear of being struck off. I have no confidence anything will improve. I can pay for investigations if I could find a doctor allowed to help me. Like a number of people with ME I am somewhat better - not completely well - when on holiday. I believe everyone with ME should be given vitamin D supplements.</p>
526	Exeter, East, Mid and North Devon CFS/ME Service	<p>These clinics have harmed many. They need to be given appropriate guidelines. NICE guidelines at present harm most people if followed. Doctors are giving the diagnosis to people who do not have ME as they tell me they regard it as a mental health condition. Local GP told me they regard ME patients with: 'more contempt than people with depression'. This needs to be urgently addressed and NICE guidelines must remove GET/CBT and provide accurate information to doctors which means re-writing the NICE guidelines and excluding the psychiatrists who have provided false , misleading and very dangerous information to doctors. They should be held accountable. There needs to be a programme of education in medical schools and post grad centres organised by doctors who understand this condition which inform medical staff that this is a serious physical multi-systemic disease and that GET is dangerous.</p>

<b>527</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>More tests needed for each area of symptoms to rule out other illnesses. Over a shorter period of time not 12 years like me.</i>
<b>528</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>I have had ME for nearly 40 years. For the first 10 years the medical profession considered me to be a malingerer and a time waster. Now I am considered time waster. My GP recently retired and all the other doctor's in the practice I have seen, could not wait to get rid of me. I have tried to see consultants many times. At some point I am told to go away as I am a waste of their time. The shortest period before I was told this is 10 mins. The longest was 6 months. As a result of these experiences, when it comes to treating M.E., I do not consider the knowledge and expertise of the medical profession to be worth a damn.</i>
<b>529</b>	Wells - Somerset CFS/ME Service	<i>The clinic was helpful in a lot of ways and it helped me with resting and coming to terms with not being able to do the things I took for granted .</i>
<b>530</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<i>This department could only advise on increases in exercise, not in whole of life management. They had no concept that this was not just some kind of extended couch to 5k programme, nor that I was chronically ill and that it affected every area of life, from my marriage, being a father, to trying to hold on to my job, to keeping friends. It was overall an extremely traumatic experience. I have never dreaded seeing a physio in my life. As a sporty person I needed them. But those meetings, the travel to them and the constant implication that failure to improve was through my lack of effort or determination rather than the inappropriateness of the treatment has been very difficult to overcome.</i>
<b>531</b>	Liverpool CFS/ME Management Services	<i>I would like to heard and seen.. I feel I have been left to rot like many others do #millionsmissing</i>

<b>532</b>	York - Yorkshire Fatigue Clinic	<p><i>It is extremely important that good doctors are involved in the treatment of all CFS/ME patients and that treatment is not left solely to occupational therapists, psychologists or physiotherapists. Doctors must be aware that they have a duty of care to CFS patients, that they must not 'fob them off' onto other services.</i></p> <p><i>In my case I was told by my GP in the early years of my illness that I had 'classic CFS' and that there was no treatment or cure and that further medical tests would not benefit me - this was not true. I was told repeatedly by my GP that I must just engage with the treatment at the Yorkshire Fatigue Clinic (which to be fair, I was already doing - and I was becoming more ill). Every single symptom I had was dismissed as 'CFS', even when there was potential for further investigation. I saw other doctors who did not hide the fact that they found my requests for help 'bothersome' at best, I was repeatedly humiliated. Many people with CFS experience this.</i></p> <p><i>Five years after my diagnosis, I had seen 8 different GPs searching for answers - and I finally got some.</i></p> <p><i>- I was diagnosed with various and severe allergies - to foodstuffs, pets, and environmental allergens.</i></p> <p><i>- I was also diagnosed with sleep apnea.</i></p> <p><i>These conditions ARE treatable and manageable. The symptoms were there from the beginning - but the initial 7 GPs I asked for help would not listen because Yorkshire Fatigue Clinic had already made a CFS diagnosis. Fortunately (sic) the 8th GP engaged with me and was prepared to request the tests that I asked for - this would NEVER happen for patients who are forced to only receive treatment from occupational therapists, psychologists or physiotherapists. They simply do not have the experience to identify co-existing conditions, or mistakes in the CFS diagnosis.</i></p> <p><i>I have endured considerable suffering that was completely avoidable. Doctors must be involved in the treatment of CFS/ME patients, and they must be aware that these patients are their responsibility.</i></p>
<b>533</b>	Essex Chronic Fatigue Service	<p><i>This survey is not relevant to my condition. I was diagnosed with ME; MCS and severe food intolerance. The Consultant Neurologist who diagnosed me said the NHS could not treat me and referred me to a private clinic. I received 6 weeks funding from the NHS and then funding was stopped. Since then I have been diagnosed with multi organ failure.</i></p>
<b>534</b>	Birmingham and Solihull CFS Service	<p><i>CBT, GET is not suitable therapy. ME is a physical problem and not caused by mental health. It can lead to mental ill health. Pressuring sufferers to respond in these therapies is inhumane. Professionals need to properly understand ME and spend a day in role play as part of their training. ME sufferers should be delivering some of the training. Sufferers should be congratulated on their achievements even if it is getting out of bed</i></p>
<b>535</b>	Suffolk Specialist ME and CFS Service	<p><i>Please help us, I feel I have no future if things continue as they are. There should be tests done that are actually relevant to M.E, specific deficits relating to mitochondrial dysfunction, hormonal, and toxins. I switched to a ketogenic diet, and it's improved my brain fog. I'm terrible at pacing. It's hard when you are severely affected and have a window of energy, it's hard not to use it all up</i></p>

		<i>and then crash. I wish there was a place I could that could help regiment diet, sleep and pacing.</i>
<b>536</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>There is a complete lack of understanding in the medic role.. the least we need is that GPs understand that ME is a neurological condition caused by inflammation.. and exercise and cbt .. cannot and do not do anything to improve this life altering condition.</i>
<b>537</b>	Not listed	<i>I was advised not to do boom and bust and that this caused a cycle of fatigue. However you cannot 'save' up energy this is a myth you have what you have. You can choose to do small activities within your energy envelope which may be very little at all or over do the physical activity and deal with the the extremely bad post exertional fatigue that comes with it. I tend to choose a rewarding activity with 2-4 days rest needneeded to recover over being stuck at home doing very little.</i>
<b>538</b>	Not listed	<i>Research is needed, the PACE trial needs to be ignored. GET and CBT have made no positive difference (and have worsened my symptoms.) A medical solution is needed, no amount of diet, exercise or psychology will mend mitochondria, increase blood flow, or regulate spinal fluid.</i>

<p><b>539</b></p>	<p>Not listed</p>	<p><i>I found the doctor Myhill approach good with pacing. Pacing within energy envelope but having at least 30% energy in the bank before sleep. Waiting until all symptoms stabilised for at least a month before increasing any activity. Treating underlying conditions (such as gut issues SIBO, intolerances, diet, testing for underlying or contributing conditions symptoms such as omega, B iron , magnesium deficiencies, getting vitamins at optimum levels (not just at minimum threshold, more accurate thyroid testing, testing for everything listed in ME ICC, using 2 day cpet to monitor PEM/PENE) The NHS completely missed my b9 deficiency and the fact that my iron was very low, but within normal range by 2 points so was ignored. Just fixing my B9 and iron really helped with some symptoms. I believe this was due to psychologising my physical symptoms, these were ignored and testing frowned upon meant that physical issues that could easily be fixed were ignored or missed. This is why a completely new approach is needed. Patients currently willfully neglected due to a psychosocial approach for a physical disease. This is irresponsible and puts patients at great risk of institutionalised harm. This is entirely the issue with current NHS services decided by the NICE and why it's absolutely vital that NICE adopts the ME ICC and ditches the defunct theory that ME cfs is psychosocial. Removing psychosocial proponents from the NICE committee and replacing them with actual specialists that understand the disease process is vital if patients are to be genuinely helped and the harm to stop. All treatments must be evidence based and use objective outcomes/measurements such as the 2 day cpet, step counts instead of unblinded trials open to bias using subjective outcomes, which has caused so much harm to patients. The correct treatment early on is a much more cost effective than pushing thousands upon thousands into long term disability. I do believe if I had the Dr Myhill advice early on, I would have remained mild or recovered. I now have severe ME because of the incorrect advice given On the NHS. As there is no known cure, prevention of severity must be a priority. I have had ME 20 years now. Current incorrect treatment and neglect has cost me and the state dearly. If we are to change this dire outcome for patients, it must be through good quality biomedical research and treatments that do not harm.</i></p> <p><i>Please adopt the ME ICC as a matter of urgency and base treatments protocols on science with objective measurements. Without the appropriate health I may never have any quality of life or chance of recovery or to return to my dream job, have a social life or family. The current services stink. They are based on unproven theories from studies with poor entry criteria (non M.E. icc) subjective outcomes and poor methodology. A patient could enter the PACE trial for example, get worse and still be counted as "recovered" as they moved the goalposts mid trial. All I ask is for is to ditch poor science and embrace the quality studies that use objective measurements and get knowledgeable doctors to guide your guidelines and treatment protocols.</i></p> <p><i>Without this vital paradigm shift, services for pwME will continue to harm thousands of patients like me and leave us with no support. Harmed then neglected, by people that are supposed to help us.</i></p>
<p><b>540</b></p>	<p>Liverpool CFS/ME Management Services</p>	<p><i>I believe the practitioners I worked with were knowledgeable and caring but were constrained by existing NICE Guidelines.</i></p>

<b>541</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The service workers knew way less about the science re ME than I did; in one course, the head of service (an occupational therapist) announced that ME was "all in your nervous system".</i>
<b>542</b>	London - Uxbridge - Hillingdon CFS/ME Service	<i>I know this is a short survey with limited multiple choice options but I'd like to mention that things aren't as straight forward. I believe that I needed a lot of rest in the first year or so of CFS/ME after diagnosis and that was important as my body had been through a lot. After that I think it was important for me to stay as active as I could without pushing myself too much and to maintain a daily activity goal. I've tried to increase it which at times has worked and others not so much but it's important to not focus too much on just activity but to teach patients how to deal with the other symptoms they have and figure out if there are any other triggers that cause them also.</i>
<b>543</b>	Gillingham - Kent CFS/ME Service	<i>When I was diagnosed with M.E. I was severe and bed bound for years, the consultants blamed me for being ill, they said it was growing pains or I was skiving off school, or I was depressed instead of educating themselves about my condition they turned the blame and responsibility to myself (then a child) and my mother. I was told to exercise and to take sugar supplements or glucose powder, which had a detrimental affect on me and as a result of my treatment I was bed bound for around five years, lost all of my schooling which I loved and I have had a hellish life where I have been left alone with no treatment unable to work or care for myself properly. I am still in a bad way 30 years later, barely unable to walk. These M.E. services are shocking, abusive and traumatic for patients. Further more many doctors add to the abuse and trauma as there seems to be a lack of education on M.E. and many doctors and consultants in hospitals are still working from the mindset that M.E. is psychological. With all the evidence and biomedical research that has been done we know that it is not. Please, STOP harming patients. Stop putting children at risk and destroying their futures.</i>
<b>544</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>It should be emphasized that just as if you were paralyzed, your life would never be the same again, but it doesn't mean no life.</i>
<b>545</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>They should be aware of the vast number of symptoms (70). It is not a static condition, it is ever changing. Some come in cycles, some come at low points, some seem to come once or twice a year only. It is not simple or static.</i>
<b>546</b>	Not listed	<i>M.E. seems by my own experience to be a physical illness not treatable using psychological methods</i>
<b>547</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	<i>I was able to manage my illness for over 30 years without needing intensive care before I was involved in this service. Taking there advice ruined my life and that of my family. It's frustrating that BCUHB hide behind nice guidance when challenged</i>

<b>548</b>	Leeds and West Yorkshire CFS/ME Service	<i>Nice need to take us into account and not just fob us off with harmful practices. The stigma of do this or there is no help, needs to stop.</i>
<b>549</b>	Stockport CFS/ME Service	<i>the pain doctors do not empathize with you ..they don't know what we go through on a daily basis. for them to say well the 90 year old lady that I saw last has had fibro all her life and she just gets on with it well she might not be as bad as me .I was disgusted.</i>
<b>550</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>More research and more staff due to increasing numbers of people with CFS/ME</i>
<b>551</b>	Not listed	<i>I believe that more in-depth testing should be available eg heavy metal testing, POTS assessment. I also think doctors need more understanding of the difficulties of accessing basic care. Home visits should be offered.</i>
<b>552</b>	Essex Chronic Fatigue Service	<i>There was only funding for 12 sessions which I had spread out over a year. Since being discharged I have not seen anyone other than my GP once a year. I think it would be beneficial for me/CFS patients to be seen at least yearly by the specialist clinic as their needs may have changed and gps aren't necessarily the most knowledgeable about the illness. I know that pretty much all clinics fall under the psychology approach, but if that can be changed to offered treatment that helps, then ongoing monitoring would be needed.</i>
<b>553</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>my initial diagnosis was at St Barts Immunology clinic in 1993 I was given a physical explanation for the condition which matches what research indicated then and confirms now I was therefore told to rest but not become inactive if possible A friend attending the clinic recovered by taking Immunovir I was going to be given it but we ran out of time as the clinic closed down and everything to do with ME went psychological  I was lucky enough years later to see a physio at the ME clinic who immediately recognised that I needed to work on rest first and wasn't in any way ready to start any exercises so I was protected from graded exercise She told me to come back when I improved and she would help me then I haven't improved so haven't been back I have therefore had no support on the NHS</i>
<b>554</b>	Birmingham and Solihull CFS Service	<i>No</i>
<b>555</b>	Essex Chronic Fatigue Service	<i>It took 2 years to get seen, after diagnosis. I already had learnt how to manage. Too little, too late.</i>
<b>556</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>Would prefer a regular review either 6 or 12 monthly as once you have reached a level where you cope you are discharged back to gp and have to go through a re referral if you have other problems. At present i am not even Monitored by a gp unless i have problems</i>

<b>557</b>	Edinburgh - Lothian CFS/ME Service	<i>I can't fault the clinic I went to, they can't do anymore than they're doing with the resources they have</i>
<b>558</b>	Edinburgh - Lothian CFS/ME Service	<i>I was told i had me/cfs and left to get on with it. Clinic was no help. Still not sure i have correct diagnosis. Advice affected my mental health. Made me feel about 90.</i>
<b>559</b>	Not listed	<i>I am a former nurse(of many years). I worked with doctors who openly mocked patients with ME. Doctors must receive education</i>
<b>560</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>The base level needs to be achieved first, which most likely means massive reductions in activity need to be achieved. This means that new levels of acceptable standards of cooking, housework and personal hygiene need to be set. Which is a very difficult stage. Often this will involve having to completely change your mindset. Only once the baseline has been achieved can you very cautiously begin increasing your daily activities. This is the most important thing that has to be emphasised and understood. Also if you are aware, in advance, that you are going to overdo things, then you should pre rest, as well as resting to recover afterwards.</i>
<b>561</b>	Birmingham and Solihull CFS Service	<i>I felt that once diagnosed and given information on pacing and an overview of what cbt was, I was discharged. At this point, I felt really alone and abandoned. Gp's don't understand the condition, so there is no support there. I would like to see on going support from specialist services.</i>
<b>562</b>	Not listed	<i>When having to deal with a marriage break up and a husband going off with someone else leaving you with no help; it would be helpful to know the service won't discharge you while you sort your life out even though they know you now can't shower or sleep in a bed due to your carer abandoning you. I feel very let down by them and very alone in this illness.</i>
<b>563</b>	Not listed	<i>I was struggling to work part-time with ME/CFS for 3 years after diagnosis; aggressive physio therapy, poor management advice and lack of pain management meant I needed a wheelchair and lost my job on capability grounds. I still need a wheelchair and can't work. From experience working with a neuro charity I see that the key to better services for MS and Parkinson's has been properly trained Specialist Nurses - they champion the condition within the Service and give timely access to advice and drug management. Many of them were initially sponsored by a Charity and then taken on by the NHS</i>
<b>564</b>	Not listed	<i>The medical profession is painfully lacking in knowledge. We are our own experts on our condition. But for there to still be such ignorance in the medical community is a travesty.</i>

<b>565</b>	Middlesborough - South Tees CFS/ME Service	<p><i>I was given 'physiotherapy' which monitored my ability to be active and advised me on activity levels.</i></p> <p><i>The monitoring was to get me to stand up and sit down repeatedly then say how I felt. This is obviously ridiculous as we all know ME symptoms can be intermittent, so why they felt this snapshot every month was appropriate or useful I do not know. As for the standing up /sitting down... Perhaps walking on a treadmill would be more appropriate if they absolutely must.</i></p> <p><i>As for advice. I was told to gradually increase the distance I was walking and the pace I was walking at each week. Utter nonsense. If you're having a bad day you need to rest, and if you're having a good day then you can let yourself do a little more before post exertional malaise would be a problem.</i></p>
<b>566</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<p><i>The clinic I attended was mainly just for diagnosis. I was referred to a CFS specialist/physio therapist whom I see on an ongoing basis every few months to get advice on how to manage activity throughout day to day life and how to improve gradually, with an emphasis on the fact that there might be a need to decrease and adjust activity in accordance to how I feel, and the fact that this is not a hinderance or a halt in progress, but a step back in order to take more steps forward. I have found the advice of my healthcare professional invaluable to my ongoing care and my maintainance of physical and mental wellbeing</i></p>
<b>567</b>	Bristol CFS/ME Service for Adults	<p><i>It was fine while it lasted but there is no follow up so I had to source my own mental health support</i></p>
<b>568</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	<p><i>I am meeting more and more people who have been given a ME/CFS diagnosis, but who actually have PoTS, b12 deficiency or vit d deficiency. Doctors don't seem to be fully aware of how to diagnose these, and stick too rigidly to lab results.</i></p>

<p><b>569</b></p>	<p>Haywards Heath - Sussex-wide CFS/ME Adult Service</p>	<p><i>I would like the specialists, GPs, neurologists, clinicians ALL healthcare professionals have the right to accurate &amp; update research &amp; are able &amp; encouraged to do their research. Question their methods &amp; criteria when so many (95%) people do not recover. I was told I would definitely recover &amp; be back to work in no time by a head specialist in Hayward's heath. Which was horrible &amp; disheartening once I figured out he really had no idea how to treat this illness.</i></p> <p><i>We need the NEW NICE guidelines to include a variety of patients experiences &amp; knowledge on what helps &amp; what doesn't help.</i></p> <p><i>Also take into account what all these knowledgeable people have documented. Dr Jarred Younger, Ron Davis, Dr James Shepard, Jess Bearman &amp; Jen Brea. Sharing knowledge helps us so much!</i></p> <p><i>To acknowledge brain &amp; spinal cord inflammation plays a a MASSIVE part in understanding this illness.</i></p> <p><i>Under NO circumstances is this illness Psychiatric/psychological!!!! It's Insane how some healthcare professionals believe this when the FACTS are out there!!</i></p> <p><i>We need more research desperately!! I'd love to get back to work. Trainee accountant out of work for 2 years!!! Unable to play with my daughter for hours as I can not cope with the stimulation. Same with meeting friends I'm unable to cope with multiple noises without my brain feeling fried &amp; confused. I feel forgotten, hopeless, very very ill, isolated, depressed, angry, weak body although I have very strong will. I just hope to god this gets recognised as the debilitating illness that it is.</i></p>
<p><b>570</b></p>	<p>Not listed</p>	<p><i>I have been ill since December 1986. Have had to learn to manage and find information myself. Later had contact with 2 clinics: in Edinburgh. then Dorset. Edinburgh briefly had useful services before PACE (access to consultant, nurse counsellors and physio-led course). This all cut after PACE. Dorset has consultant, GP specialist, and team of OTs - but not geared to long term ill and not very well informed. Biomedical research is key to change. And need to find ways of communicating to health professionals!!</i></p>
<p><b>571</b></p>	<p>Not listed</p>	<p><i>I really wish that in this country, ME/CFS would be recognised more as an actual physical illness, and taken far more seriously than I believe it currently is.</i></p>

<b>572</b>	Brighton - Sussex Paediatric CFS/ME Service	<i>After waiting almost 3 years to get a diagnosis and referral to the Sussex clinic, I was terribly disappointed at the lack of support available. I was surprised to find harmful or ineffective treatments (GET/CBT) being offered since my reading and careful observation of my own experience had already told me these weren't appropriate. At the time I would have liked concrete information on what was causing each of my many different symptoms, and where possible, a medical-based approach to treating them. Instead there was a definite reluctance to discuss the pathophysiology of the disease, and those who declined the behavioural treatments were pressured to undertake them and frowned upon if they declined. The most appropriate advice patients received was on pacing but since I was already doing this there was no further help (discounting GET and CBT which I declined). The location of the service was on the outskirts of a hilly residential area which made accessing it difficult. My abiding memory of the staff was of them being poorly informed about ME and hostile to patients who questioned the treatments on offer. In hindsight it seems as though a terrible amount of money was being wasted providing treatment that potentially harmed patients. The only good advice, ie. on pacing was simplistic and could easily have been provided by a GP. I was offered 6 'visits' to the clinic but ultimately was too unwell to attend all of them. There was no follow up to see how I was, or alternative arrangements for severely ill patients. Since then I have received no further specialist support for ME via the NHS and have been forced to seek the support of a private medical specialist. To my mind, patients would be best served by GPs receiving proper training on the diagnosis and treatment of ME -- being allowed to undertake thorough investigations, and to experiment with different medications to treat sleep problems, pain, orthostatic intolerance, viral reactivation etc. Counselling - not necessarily CBT - should of course be made available to those who are finding it difficult to adjust to living with a debilitating, multi-system, chronic disease. Home visits should also be available to the 25% of sufferers who are housebound or bedridden.</i>
<b>573</b>	Not listed	<i>The M.E support group has been a lifeline. You don't realise how isolated you can become, losing work, friends social activity. Maybe this is something that should be addressed. Thank you.</i>
<b>574</b>	Birmingham and Solihull CFS Service	<i>Both rest and finding a sustainable daily level of activity are equally vital - I would have liked to choose both answers if I could</i>
<b>575</b>	Not listed	<i>I paid for the course at the North West chronic fatigue clinic in Preston. I was told by the lady who had worked with me (ot) "that I would be better now if I'd followed the program" I'd spent all that money to be told that, followed it by the book really upsetting. [Redacted] was her name, she left the clinic. I've spent all my savings on trying to get better. This condition is life changing there is very little support. The stigma needs to go and the medical professionals need to except its a physical disease and because of the nature of it causes the anxiety and depression.</i>
<b>576</b>	Bristol CFS/ME Service for Adults	<i>I would want some continuation of care/interaction instead of being abandoned</i>

<b>577</b>	Derby - Derbyshire Chronic Fatigue Syndrome (CFS)/ME Service (Adults)	<i>Derby clinic did their best within the constraints of treatment and time available.</i>
<b>578</b>	Not listed	<i>GP's are still calling it 'yuppie flu'. They appear to be very narrow-minded. There should be ME/CFS clinics in the NHS as there is now a fairly international acceptance of this disease, in advanced medicine.</i>
<b>579</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>I think that people with ME should listen to their own bodies and pace. Pushing yourself outside of your limits, especially when you are getting many symptoms, is very harmful advice.</i>
<b>580</b>	Not listed	<i>My OT was and is excellent. How can ME/CFS be understood and properly compassionately cared for if GPs are not trained using the most up-to-date scientifically proven research. A US doctor who treats HIV and ME/CFS patients said he'd rather have HIV because it was well researched, understood and curable rather than dismissed. For example, it would be scandalous neglect if an MS patient was left undiagnosed, untreated, told their condition or fatigue weren't real and had to pay privately for tests and treatments to see if they could help themselves improve. Why should this condition be any different? One GP told my mother to "make me get out of bed, she"s only 47" when I was completely paralysed. Shameful treatment of chronically ill patients because of lack of knowledge and or ignorance and arrogance.</i>
<b>581</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>I have been successfully self medicating for nearly 2 years with diet and supplements. I don't believe the medical profession will back track on their position that ours is a psychological problem not a result of toxic stress overload..</i>
<b>582</b>	Liverpool CFS/ME Management Services	<i>I was told that I WOULD recover, as long as I complied with GET - and if I didnt recover it was because I didnt try hard enough. Literally.</i>
<b>583</b>	Not listed	<i>A very misunderstood condition by most GP'S and the DWP for benefit purposes</i>

<p><b>584</b></p>	<p>Not listed</p>	<p><i>I tried even the mildest Pilates with a very experienced and personally responsive teacher at my own expense who did additional research in M.E.</i></p> <p><i>I enjoyed it and persevered for 2 months but even though the activity level was dropped down and down, very gently but I found it impossible to sustain at that time and felt delayed crash the next day for 24 hours.</i></p> <p><i>I found being continually focussed on recovery unhelpful and detrimental. No one wants to be "stuck" in the illness phase but it's like struggling to get free of a bet and I find consciously trying to get well just doesn't work for me. Some claim it does. I do want to be well and normal like so used to be but even pushing slightly sets me back into a worse position. Therefore I relax back and have had to learn to accept and work within the parameter my brain has set.</i></p> <p><i>Pacing sounds logical and sensible. I can manage what I know I need but as I stated at the time, I could only manage placing to my level if I was free of the expectations of work and my employer a county council (as I was trying to hold down my job at that time ). This sadly is a consequence of being told by a consultant that he had not seen positive outcomes for those who had given up work. Remaining in work was torturous, I ended up on disciplinary processes which added to stress level and reduced self esteem even more. Whilst the council was moving towards horseshoes and was working from home I was so stringently managed to attend the central base I couldn't sustain and kept collapsing. Their actions were creating the very position they said they were trying to avoid. Therefore, pacing failed. Because you can't manage the expectations of others.</i></p> <p><i>The treatment programme overall in hindsight had practical and helpful elements such as sleep hygiene, using pillows for support and so on to help make one more comfortable. What wasn't covered was or supported was support to transition from what one was to being what one has become. Acceptance of one's situation was stressed again and again yet at the same time, trying to make steady improvements when the rest of one's life is unsupported. So MUCH is being asked and put on the patient to get sorted, it's mostly impossible. When I look back I don't know how or why I put myself through what I had to go through. It was an extremely painful experience and even though my family were telling me to give up work, I couldn't. I was helped as to how I could achieve it. Benefits would not lock in. I couldn't access my pension at the time of onset of illness. I just didn't have the energy and mental resources to try to sort it out. It therefore escaped to crisis levels to enable a way out.</i></p> <p><i>I have found the technique of staying to try awake by changing track on any activity I'm doing for 20 mins to something else helpful. This includes reading, mental or physical activity.</i></p> <p><i>More updated training available to clinical staff reflecting modern thinking on M.E.</i></p> <p><i>I found even the old NICE guidance wasn't followed. It took 18 months for me to receive a diagnosis. I couldn't deliver certainty to my employer, it went on and on.</i></p>
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<b>585</b>	Suffolk Specialist ME and CFS Service	<i>Current services only allow for a certain number of appointments and then you are discharged. It should be that we have support throughout the illness as long as we have the illness and not limited support!</i>
<b>586</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>Continued support but I feel very frustrated with myself unable to do very much.</i>
<b>587</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The service when running initial introduction to pacing did not incorporate any time for socialising with other attendees - contributed to feeling you were only "a number" not a named individual. Socialising was actively discouraged in order to save energy to focus on the information. Group CBT was more helpful in discussions &amp; identifying alternative coping strategies.</i>
<b>588</b>	Edinburgh - Lothian CFS/ME Service	<i>More research is needed into biological causes so more focus on this can be done for potential recovery. Also the ME service I attended I felt were good in regards to taking me seriously and although only offering management through psychological services never once made me feel as though this was all just in my head.</i>
<b>589</b>	Leicester CFS Service	<i>I feel forgotten any other illness you would have regular check ups when I go my doctors she looks at me like I'm an alien either that or blames me for everything gives me a prescription and sends me on my way my mental health is a mess no one to talk to or help me it'd a disgrace in comparison to other countries who invest in me/cfs we are the forgotten x</i>
<b>590</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>I have found that there is a danger of healthcare professionals perceiving ME as a mental illness or a psychosomatic issue and that this is inadvertently reinforced by the naming of the coping mechanisms course that is provided under titles such as "therapy" or "counselling." This permeates out to the general public as well to reinforce the stereotype that ME is a mental/psychosomatic issue. This is one of the biggest barriers I face both with healthcare 'professionals' and in life generally. If greater care is taken with such phraseology, particularly when healthcare professionals are educated (a considerable gap in itself), then this problem could be mitigated and would lead to a far better understanding of those with ME.</i>
<b>591</b>	Liverpool CFS/ME Management Services	<i>I have been left to figure the condition out myself. The clinic requires you to go to 3 appointments of PowerPoint presentations, each appointment being a couple of months apart, before you are accepted for one to one help and guidance. If you miss an appointment you are discharged and have to start all over again. This instantly discriminates against moderate to severe patients leaving them with no support. In my experience other healthcare professionals are afraid to give advice, because they believe the clinics are doing their job and believe them to be the experts. The system desperately needs addressing.</i>

<b>592</b>	Shrewsbury - Shropshire Community Neuro Rehabilitation Team	<i>I had to gain control over my ME as I'm single with 2 young children. The activity is hard physically and mentally if hadn't been for my children needing me I would've gone back to bed and said it was too painful to do &amp; stopped the disciplined regular increase in activities. However I persevered and thank god I did as now years later I am in control of my me. I know what I can do I plan ahead, I sleep regular hours I do a similar level of exertion daily I'm at the point I can now cut my own lawn! Those that don't try are an embarrassment to other ME sufferers. I've pushed myself physically and mentally and it has paid off, I can lead a relatively normal life if I do the same amount everyday regardless and weekly include a slight increase. I can't go running or skiing but I can make my own meals, tend to my own housework and do my own gardening. If I don't do housework I go for a short walk. I can help my kids with homework go watch their plays and sports days. Without sheer determination and the advice I'd still be in bed asking others to do normal daily tasks like washing ironing etc.</i>
<b>593</b>	Nuneaton - Warwickshire CFS Service	<i>Experiences of M.E are v diff i feel there wasn't an approach to help many options.</i>
<b>594</b>	Liverpool CFS/ME Management Services	<i>I am still waiting to see a specialist at the clinic some 2 years after being diagnosed by a doctor and it took nearly 10 years for that diagnosis, even with a diagnosis and attending pointless apt's at a clinic I am no further on at understanding or managing the condition just left with this horrible illness alone</i>
<b>595</b>	Middlesborough - South Tees CFS/ME Service	<i>The specialist nurses were much more understanding of the practical points of day to day management than the initial consultant. The doctor suggested that M. E. only happened to certain personality types and that it was the result of burnout. I have yet to find any studies supporting his view and it made me feel like it was my fault for developing CFS. Unfortunately since I was unable to complete the course due to a separate illness of flu, I have not had any medical help since 2005. And don't know where to get any further help that would provide me with any up to date information about improving my health.</i>
<b>596</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>the lack of biomedical investigation (endocrinology / immunology / genetics) is a real gap</i>
<b>597</b>	Leeds and West Yorkshire CFS/ME Service	<i>All my doctors after the first advice agree that it was trying to exercise my way out of ME that resulted in my being hospitalised and still being ill after 30 years +. CBT is patently not a cure for ME from my experience.</i>

<b>598</b>	Nuneaton - Warwickshire CFS Service	<p><i>I believe there's not enough support for people like myself. My life was destroyed when I fell ill and years have gone on with no actual good help/advise from health care professionals to help me improve. The illness isnt properly understand and I feel judged more often than not.</i></p> <p><i>I cant travel far but my nearest clinic/specialist is 40mins to 1hr and i cant travel that far on my own or rely on others to take me. I really feel that home visits would be beneficial for ones like myself who have moderate to severe cfs/fibro and find it hard to attend things.</i></p> <p><i>And the DWP/PIP treat us unfairly</i></p>
<b>599</b>	Not listed	<i>CBT &amp; GET are not methods for treating ME/CFS we experience physical pain and fatigue. Please stop telling us that by doing either of these methods will help as in my experiance it does not. We need proper research into why we have this chronic illness.</i>
<b>600</b>	Fareham - South Coast Fatigue	<i>Can offer more help and advice and treatment. To be more understanding and offer more courses and support.</i>
<b>601</b>	Not listed	<i>My clinic was in local drs attended by an occupational nurse with little help and advice , I was severely disabled by the illness and she seemed at a loss what to do</i>
<b>602</b>	Hull and East Yorkshire CFS Service	<i>My parents had to persevere for a long time with our local surgery to persuade them to fund my treatment in Hull as there is no treatment available locally.</i>
<b>603</b>	Not listed	<i>many of the healthcare professionals in these services mean well, but are unable to do their jobs well due to outdated guidelines and a lack of up-to-date, easy-access information.</i>
<b>604</b>	Peterborough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<p><i>I have learnt living with this for 11 years now that the thing that works best is knowing my body, becoming so self-aware that I can notice the smallest trigger, early warning signs of a flare up. Adaptation and managing expectations are extremely helpful. Mindfulness is wonderful strategy. Ultimately if you have M.E. you have to put up with professionals not taking you seriously on a continuous basis. Learn to be your own healthcare professional. Luckily I am already which gives me a helping hand. Researching yourself, reading published articles, learning to evaluate them for quality and validity. Be your own detective and be meticulous with record keeping.</i></p> <p><i>It's time for more research funds!!!!</i></p>
<b>605</b>	Bristol CFS/ME Service for Adults	<i>I feel like the questions were rather closed. I am not sure I have answered as clearly as I could have. I have just started a new course at the ME clinic (only one session so far) which feels a bit better than the past 'support'. However, I still feel misunderstood and not supported fully. I had to continue working and studying in order to be able to pay my rent and eat. I have got worse because of this. The most supportive thing would have been having benefits whilst I rested and got better. I now feel the ME has got too bad and I may never recover.</i>

<b>606</b>	Leeds and West Yorkshire CFS/ME Service	<i>Leeds M.E service is not fit for purpose. They think we are all mentally ill.</i>
<b>607</b>	Not listed	<i>I feel like there is nothing they could have done to change my situation. I have a better understanding of why I get fatigued, but as someone who has been ill for a long time, I had already learned to adapt to ME/CFS by myself. I imagine this is useful information for someone who is new to the illness, but I don't see what help they can be after that. I do not feel there is much point in visiting the clinic any more than I have. I know there's no cure, but it makes me feel helpless and disillusioned with the health service. It's reassuring that they aren't peddling GET and such, at least at the clinic I went to though.</i>
<b>608</b>	Dorchester - Dorset Children and Young People's Chronic Fatigue Service	<i>Wareham Hospital ME/CFS clinic not listed so I used Dorchester. I attended in 2001 and 2014- CFS/ME is physiological and needs an appropriate physical approach. Like many illnesses, some appropriate counselling may be helpful too. Most effective treatment by far for me has been Dr Sarah Myhill's mitochondrial approach.</i>
<b>609</b>	Not listed	<i>There needs to be clinics lead by Consultants who specialise in treating patients with ME and not just as a sideline to their main specialisation. For example when local services began, I was seen by an Endocrinologist who confirmed I had ME, tested and treated me hypothyroidism (which had no impact on my ME). That was 10 years ago and I haven't been seen by him again. As with the majority of patients suffering from this dreadful and misunderstood disease, I feel abandoned with no hope of any future treatment and minimal funding put into research.</i>
<b>610</b>	Not listed	<i>My clinic wasn't listed it's Green Lane Clinic in Durham. All I get told is to pace and rest. While it helps a little, I wonder whether anything else is available to help?</i>
<b>611</b>	Connah's Quay - Betsi Cadwaladr University Health Board East CFS Service	<i>I have tried to access a drug known to help alleviate the fatigue given to those with MS &amp; haven't got anywhere with the gp on eligibility for those with ME, or why its not prescribed to us for certain circumstances?</i>
<b>612</b>	Not listed	<i>GPs don't know enough. I wasn't diagnosed by three GPs, finally by a specialist I myself found. This meant years of doing too much and doing permanent damage so I'm far worse than if I'd had pacing recommended by anyone in the first year. Your questionnaire is wrong with "increase week by week" - this is way too fast; and it is not clear that you show CBT does not help with anything but dealing emotionally with the devastation this disease causes. Did you ask anyone with CFS to review it before posting it?</i>

<b>613</b>	Birmingham and Solihull CFS Service	<i>I have been ill for 15 years and it was only after a severe relapse two years ago that I received any investigation into my health. It took 14 years to meet a health professional (a GP) who took an interest in the illness and understood it. She is the first person to tell me to rest. I have still encountered doctors who have told me "to just sit up" (I am bedbound) as recently as last year. A neurologist told me there was nothing wrong with my body and that ME was a functional disorder. Most neurologists and nurses were kind but very ignorant. They did not understand how bad the hospital environment is for ME patients. I currently cannot receive tests I need in hospital because I cannot sit up and the ambulance service does not cater for that in an outpatient setting. I wish my illness was treated with the understanding and compassion of other neurological illnesses like MS, because the health service wouldn't become something dangerous to avoid but could actually look after patients appropriately. GET needs to be dropped ASAP. It is the very worst 'treatment' to offer. We have been neglected and mistreated for so long and each new sufferer learns the hard way how bad the current situation is.</i>
<b>614</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>I haven't answered the last questions because I haven't received that advice yet. I will in the next few weeks. I've been ill for 2 years so receiving such advice a lot sooner would have been helpful. I keep reading about research into ME coming out of the USA and it feels as though research and services in the UK are a million miles behind. It scares me.</i>
<b>615</b>	Dunstable - Bedfordshire Chronic Fatigue Service	<i>With most GPs knowing little about the illness, seeing a 'specialist' consultant once is not enough. Being able to build a relationship with a specialist, even a specialist nurse, over the longer term would be really beneficial.</i>
<b>616</b>	London - Uxbridge - Hillingdon CFS/ME Service	<i>I think it may be possible to improve health through very gradual increase of activity (not "exercise" as it is conventionally understood) but that this can only be achieved by working one to one with a physio who is experienced and trained in dealing with ME/CFS and who has the time and resources to work with you over a long period of time (probably years). I don't see how the NHS could ever fund this, so working with a private physio would be the only option. This will exclude the majority of patients from accessing treatment.</i>
<b>617</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Appointments by skype were more convenient but felt like tickbox exercise and did not feel like treatment. However they were essential for updating and keeping school informed and "at bay" in relation to non attendance at school. CBT was arranged by the service but delivered by local cahms team who had little or no experience of CFS and delivered standard CBT for 2 sessions before advising there was no need for this treatment as no anxieties displayed to work on. Low BMI was identified by the service on the first meeting and we had an emergency admission to hospital but released next day and no follow up available to help with this.</i>
<b>618</b>	Suffolk Specialist ME and CFS Service	<i>With hindsight, I would have done better not attending the specialist clinic. It was almost a complete waste of time and energy. Out of six weeks input, there was only one suggestion made that was useful.</i>
<b>619</b>	Not listed	<i>Ayrshire Scotland has no proper Me/CFS facilities. I'm currently left to my own devices and no longer under any NHS care. Simply forgotten about and left to rot.</i>

<b>620</b>	Hull and East Yorkshire CFS Service	<i>To make aware that everyone living with ME / CFS need to have support from a health professional and to feel listened to and more readily help should be provided for those who continue to work despite the brain fog they live with on a daily basis</i>
<b>621</b>	Not listed	<i>Paediatrician refused to call it ME/CFS. He calls it perplexing and unexplained fatigue. He doesn't believe the pain in legs.</i>
<b>622</b>	Newcastle - North of Tyne CFS/ME Service	<i>This is not a one size fits all approach. Doing the simplest task one day may have a detrimental effect, doing to much if you "feel slightly normal" can have an awful effect and some us are hard wired to try therefore causing more malaise and chronic symptoms. Being left to own devices also not helpful, should be seen at least yearly or two yearly to monitor symptoms. My experience is you have this, there is no cure and your bloods look ok. I am not.</i>
<b>623</b>	Bristol CFS/ME Service for Adults	<i>The clinic has not told me to increase my activity levels purely as I seem to have a progressive form of M.e even though they refuse to acknowledge its progressive in nature. They are also know I am aware of the many people's lives that have been completely and permanently ruined by G.e.T. They would have otherwise got me to do what they claim is "safe G.e.T". Obviously, G.e.T being based on flawed theory and flawed evidence, there is no such thing as "safe G.e.T". It's either UNSafe G.e.T or not G.e.T at all!</i>
<b>624</b>	Not listed	<i>Pacing im ones day is paramount day by day.</i>
<b>625</b>	Not listed	<i>I have been ill for 26 years, 10 of those bedridden and twice critically ill. I have, at times, been treated with derision, blamed for my own symptoms, accused of not wanting to get better, referred to a psychologist, been accused of anorexia, denied welfare benefits, home visits from a GP, home care (despite living alone).....I could go on. I have received no helpful advice on how to cope with my symptoms and no helpful treatment for any symptom, from pain to insomnia, in the entire time I've been sick. The treatment of ME patients, particularly the long term and severe, is a national scandal.</i>

626	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<p><i>More awareness and research about ME/CFS needs to be implemented especially in the medical field. I've previously been laughed at, disbelieved and my diagnosis ignored by medical professionals and told I have stress and anxiety. As previously stated more awareness of the disease, more funding and more training and awareness on the latest research results is essential. Updating NICE guidelines to reflect the latest research and that GET, CBT and other approaches do not help but rather hinder a person's progress, as does giving tons of medications for every symptom. Also GPs should adopt a more flexible approach in complex cases where there are more than one diagnosis's as every symptom experienced is generally blamed on ME/CFS which is to me a dangerous practice. I think social services should be included in the multi-disciplinary team as should a member from the persons work establishment. Too many people suffering from this disease are forced to work the same hours as a healthy person and the end result is they are forced out of work. The PIP assessments need specialists conducting the assessment who understand the disease and its limitations on a person rather than someone telling the diagnosed person to touch their nose and toes or get a house maid!! A more helpful approach to claiming universal credit/benefits system, especially for full-time students with the diagnosis is a must. Once unable to work people with ME/CFS easily become isolated in their own homes and this adds further risk to their overall health especially if they do not have family or friends to help or check up on them. This can easily make us missing on all services radar therefore better services are required all round really, better understanding and funding. A specialist home service should be on offer not just the basic care as offered by social services as this deskills a person and in ME/CFS this could be disastrous. A deeper look into the deaths of ME/CFS patients worldwide should be completed by a specialist task force to see exactly where all professions available to help the person have failed and suggestions on improving on these failures made public worldwide.</i></p>
627	Bath Specialist Paediatric CFS/ME Treatment Service	<p><i>I found that booming and busting was the worst thing I could do. I needed to maintain a level of ability. If I became unwell I needed to allow for longer to recover. Listening to my own body allowed me to go from sleeping 23 hours a day to university and full time work.</i></p>
628	Newcastle - North of Tyne CFS/ME Service	<p><i>I strongly feel that PWME should rest in the early stages and during any relapse or heightened immune system state and when they are able practice pacing and learn to understand that physical, mental and emotional activity costs energy and that what counts as rest one day may cost energy another day. Underlying physical cause needs to be accepted and understood before we can get anywhere. Stop looking at fatigue and concentrate on all the anomalies unique to ME. Stop lumping in people with chronic fatigue with ME, it muddies the water for genuine PWME and the chronic fatigue people probably have perfectly diagnosable conditions that doctors can't be bothered with or afford tests.</i></p>
629	Sunderland - South of Tyne CFS Service	<p><i>Early diagnosis would be beneficial to sufferers and also for GP's to believe in the illness as I was told by the Head GP in my surgery he didn't believe in ME/Cfs</i></p>

<b>630</b>	Leeds and West Yorkshire CFS/ME Service	<i>Yes the me clinic in Leeds need a massive rehaul it's letting it's patients down we should t be begging for help and chasing them</i>
<b>631</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<i>This was sadly a service that at best was ineffective, but actually positively harmful. The clinic didn't follow up why I dropped out or mention or monitor harm. I was actively advised not to go online and seek support from charities and other groups, depending a sense of isolation and dependence on the service. Having experience poor care, bad advice and deterioration, I felt deeply betrayed by my GP and the Clinic (supposedly a listening service) for not listening to me and seeking to understand &amp; offer real support. I still do not fully trust healthcare professionals to have a basic understanding of this illness and it presents a hurdle to be overcome at every consultation.</i>
<b>632</b>	Torquay - Torbay and South Devon CFS/ME	<i>The inability of the NHS of treating the most severely affected at the same standard of care and ability as those able to attend clinic regularly is shocking. That's like saying they'll treat a fracture but not a broken arm hanging on by a bit of skin. Extreme I know but that's how it feels.</i>
<b>633</b>	Not listed	<i>Follow up information or upto date advice as 14 years later no more help after initial clinic.</i>
<b>634</b>	Sunderland - South of Tyne CFS Service	<i>I also think it a disgrace that once you have been diagnosed, you are left to cope with the condition on your own. I have tried to see specialists over the years, and been told no. So you feel so alone.</i>
<b>635</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Your questions don't have enough options. When you ask about the advice given 'whilst I felt ill', there was a distinction in the flare plan between ME symptoms (rigid increase of 10% a week) and getting a cold or whatever (have a couple of days off then back to the pacing). There wasn't an option for not following the advice of the healthcare professional (because it was very quickly clear it made things worse). The best advice would have been more adaptive pacing, dependant on other external factors eg stress at school etc.</i>
<b>636</b>	Newcastle - North of Tyne CFS/ME Service	<i>Twenty years ago I first came to be diagnosed. In twenty years the treatment has remained the same, despite such severely sick people living miserable lives. I've heard people have benefited from saline drips and a number of medical treatments that ease symptoms which are only available privately in the UK.  Every year I get worse and neglected by the medical establishment. I'm an Admin on a global ME Facebook page and the suffering I see daily is enough to make you weep. We've also lost members to suicide, infact it's common. It needs to end. We need help. We need new guidelines.</i>
<b>637</b>	Bath Centre for Fatigue Services	<i>ME is a physical autoimmune disease, it needs to be treated as such because the neglect, abuse and gaslighting of ME patients is shameful. I'm a registered nurse and would always go to, and trust, NICE guidelines. No longer do I trust them, following those guidelines has made my illness worsen markedly. I will never forgive them. All I want is my life back!</i>

<b>638</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>Waiting times for extra therapy - ie CBT very long (over a year). Feel like your left too it once you've had initial pacing advice!</i>
<b>639</b>	Bath Centre for Fatigue Services	<i>Just because they don't know how to help shouldn't mean we are forgotten and dismissed by our healthcare professionals. Care about our lives. Please. Give us something to grab hold of, something to say 'i am getting some sort of help and being listened to'. Counselling sessions, time with a professional to look at medical studies and advances in other countries as well as regular blood tests, irregular stuff checked, better tests for all the other multitude of illnesses this could be mimicking etc etc etc. Just help us.</i>
<b>640</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>My CBT therapist was lovely as was the physio but both courses were pointless. The dr in charge of the unit was extremely unhelpful and unpleasant and I was just left with no contact after I was unable to continue with my graded exercise.</i>
<b>641</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>The therapy took me from an I'll person with M.E and a positive outlook and determination, to a person who became suicidal at the gaslighting and I was then given a NEAD diagnosis on top...it seemed if I hung about long enough I'd just get more and more clinicians who support the same psychological theories giving me more and more labels...and resistance to this would be seen as non cooperation that I was making my symptoms worse by that...it was awful, very damaging and the letter my consultant wrote [redacted] implied if make a full recovery if I gave it to all this therapy again in the future.</i>
<b>642</b>	Not listed	No
<b>643</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<i>The advice I was given was often totally impractical in relation to my work and lifestyle. I was struggling to keep going in a high powered and pressured job and certain suggestions, eg: that I should take regular breaks, of about ten minutes at a time, during the day to simply do nothing, were impossible for me to achieve. I could not refuse to answer my telephone or respond to a colleague or client. Also, I was told to avoid the 'boom and bust' syndrome but I have found that I work better that way - using up my energy while I have it and then paying for it later. I may have to stay in bed for a day or two but I will have achieved something or have a lovely time to look back on. If I sit down to rest in the middle of an activity, I will not return to the same energy level I had before. I will still be exhausted but will feel depressed that I haven't finished what I was doing.</i>
<b>644</b>	Sheffield CFS/ME Service for South Yorkshire and North Derbyshire	<i>doctors are woefully ignorant on this condition and they need educating. the nonsense about it being a psychological condition needs to be addressed and patients need to be listened to. more funding is needed to find a cure.</i>

<b>645</b>	Middlesbrough - South Tees CFS/ME Service	<i>I found it extremely difficult to get to and from the clinic and spend two hours there; the subsequent PEM kicked in to such an extent that I had to question whether it was worth it. The best thing was the mutual support that developed between participants - sharing experience and tips was really useful as out of the clinical team, only the specialised nurse knew what she was talking about. The physio had no understanding at all.</i>
<b>646</b>	Sunderland - South of Tyne Paediatric CFS Service	<i>More sympathetic doctors for children with ME! We had some horrendous experiences. Also schools should get awareness training as they are also very unsympathetic.</i>
<b>647</b>	Not listed	<i>I think severe ME needs better understanding it didn't seem understood that sometimes in a crash I couldn't move, or open my eyes, I was so tired I was scared I was going to stop breathing . Also just because I refuse CBT and GET which I find detrimental I was told I don't want to get better I think it needs to be respected when patients say no sorry that didn't work for me . Also I just feel left by the NHS 95%housebound at 29 no support no help fallen through the cracks a lot of the time too sick to go to the doctor's . The lack of understanding and empathy in A&amp;E is just amazing .</i>
<b>648</b>	Not listed	<i>Cfs me services on the NHS in the midlands are a disgrace and make us suffer more</i>
<b>649</b>	Newcastle - North of Tyne CFS/ME Service	<i>In team answer limited to 3 choices I wanted a dietitian too. That help early on May have prevented some secondary problems I ended up with. I am highly motivated to exercise but it was 8 years before I got a consistent enough period to increase my activity. For no apparent reason after a few months I started needing to sleep in the daytime again. Then lost the ability to exercise. The illness is now as bad again as when first diagnosed. This is a fluctuating illness so the ability to act on advice varies hugely</i>
<b>650</b>	Portsmouth Chronic Fatigue Syndrome Service	<p><i>I have had many different experiences with Me/CFS services, from an early group for children run in Havant to the more recent Portsmouth clinic and am great-full for the increased understanding of the illness, its impact and focus on managing daily tasks rather than increasing exercise at any cost (as I experienced at the havant group).</i></p> <p><i>However the general experience of dealing with GP's and in particular school nurses has left the bar for support services at practically ground level. The Portsmouth support service does brilliant work and was seen as a lifeline by the other people with ME I might through the service, but it was unable to offer anything to people it felt were already managing their symptoms and could offer no practical support only attendance based courses, which were 1-2 hrs long and I had to ask to lie down in the mindfulness course i attended, not ideal for ME!</i></p> <p><i>I feel that there is a gap the the only moderately ill and self managing fall down and are left in as the support services do not know what to do with them.</i></p>

<b>651</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>the service was useful in that they stressed how long the recovery period might take and everything would take a long time.</i>
<b>652</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>It's a desperately under funded service with very long waiting times which impacted on my mental health significantly. I'd also welcome more support to educate employers as this is still a massive challenge I end up doing too much despite trying to educate my boss and colleagues there is still a great deal of misconceptions and prejudice about the condition.</i>
<b>653</b>	Not listed	<i>I've had ME/CFS for 30 years+. No medical advice was available for the first 10 years (during which I made my symptoms far worse than they needed to have got through over activity.). I figured out pacing myself before it became standard advice. I am made MUCH worse by GET (1 year bedbound as a result), I found CBT (with no GET component) psychologically very helpful. NB Combining CBT with GET (and not describing it as such) means many patients will not get the benefits of CBT and are actively scared of having it.</i>
<b>654</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<p><i>I fear for the young people with ME attending this clinic &amp; feel that there MUST be a different program for those with 'CFS' or Post-Viral Fatigue - those who do not meet ICC-ME criteria- as well as taking the 'Medically Unexplained Symptom' subject and/or protocols to 'treat' FND out of these clinics for those with ME entirely. As ME is not FND or MUS and it is essentially the patients misdiagnosed [labelled with 'CFS/ME' despite having a different condition e.g. Arthritis or another Chronically Fatiguing disorder. I.e. functional disorders or depression] that make progress with the treatment options currently offered by the NHS that are harmful to 'classic' ME patients; resulting in confusion and disbelief in Myalgic Encephalomyelitis on a international scale.</i></p> <p><i>Psych assessments are understandably necessary but sufficient guidelines must be put in place for GP's to distinguish the difference between a psychological or organic illness and offer support or referrals for those who have trouble accepting the fact that they have ME or don't have ME (if they've been diagnosed with a differential disorder which may be difficult to understand if they've lived with what they thought was ME for multiple years or decades!) Counselling should be a secondary not primary treatment option &amp; should not be forced on those who fit the criteria for ICC-ME unless they have a secondary mental illness.</i></p> <p><i>I feel this is essential if we have any hope of moving forward. But there must also be a separate program or advice given for those with FND or MUS to avoid negligence &amp; discrimination. Everyone should have access to the information &amp; treatment they're entitled to.</i></p> <p><i>An ME &amp; comorbidity clinic should also be taken into consideration if "ME/CFS" Clinics continue to turn away patients with POTS, Gastroparesis &amp; Mast Cell Activation Disorders which tend to correlate with ME severity and progression.</i></p>

<b>655</b>	Oxfordshire CFS/ME Service	<p>1) The physiotherapist told me that almost all her patients recover which I found surprising as I had been told and read that there is no cure and as soon as it became clear I was not getting better I was discharged rather abruptly. 2) The psychologist I saw for CBT at the same ME/CFS clinic not once used the term ME/CFS but talked about patients suffering from different kinds of fatigue and that my fatigue was due to psychological reasons and that with GET I would be able to slowly improve my fatigue level. I chose not to return after my first visit as I did not get the feeling he believed ME/CFS is a biological disease and I did not think I could work with him under those circumstances. 3) I would like for GPs to receive up-to-date information about the disease/research and it would be nice if they actually believed the disease is real. I stopped going after my last visit when I asked for a yearly consultation as suggested by NICE to ascertain my level of health. This particular GP told me outright that there is no cure, no treatment and that there is nothing he can do for me. I feel neglected by the medical field and frustrated as to how to get better as by now I am housebound and don't know who to turn to for help.</p>
<b>656</b>	Liverpool CFS/ME Management Services	<p>It was the understanding of my condition, the acknowledgement of my condition and the ability to explain my symptoms by the therapist that I found most helpful. So it was the therapist herself and not the CBT that helped. I have not improved long term despite trying countless therapies etc that claim to help even all these years later but I do acknowledge that having someone there who really understood what the condition was helped and prevented me becoming depressed about it. As for GET, I asked my GP for a referral years ago and she just told me to look up exercises online. I have tried and continue to try increasing physical exercise but up to now each time has ended in worsening of my symptoms. I have moderate CFS - about 40% of my previous functioning, therefore can do some exercise but it's always at the expense of other activities such as seeing my grandchildren. Finally, if deconditioning was a cause then this would not explain why I can occasionally have some days when my energy levels are much improved. Of course on these days I want to do anything I can and find it difficult to hold back which is not helpful. This also shows that motivation is not an issue. I want to do so much but just can't.</p>
<b>657</b>	Newcastle - North of Tyne CFS/ME Service	<p>The physio just waffled. No plan except to try and walk more. He knew little about M.E. The clinical psych appointment had to be by phone. She was helpful and understanding. CBT not mentioned.</p>
<b>658</b>	York - Yorkshire Fatigue Clinic	<p>close all clinics that only provide psychological treatment. Need physiological tests and treatment. Test for POTS.</p>
<b>659</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<p>I hope some sort of support continues to be offered and more research is funded. Many of us are now not working or contributing to society. It's sad.</p>
<b>660</b>	Leeds and West Yorkshire CFS/ME Service	<p>Would like more specific treatment after the ten visits to Seacroft as my GP admission that he does not believe ME is a condition</p>

<b>661</b>	Norfolk and Suffolk ME/CFS Service	<i>This is a strange questionnaire. Looking at activity levels seems almost irrelevant when my sole efforts were directed towards surviving and earning a living whilst coping with a disability that no-one understood or cared about. GPs did not understand and seemed bored. There is no support. I don't see how advising people on activity levels is going to resolve anything for them. People already have a sense of what they can cope with.</i>
<b>662</b>	Middlesborough - South Tees CFS/ME Service	<i>Clinics should take an interest in up to date biomedical research, treat symptoms, and inform patients that psychological therapy is not the answer. Being made to feel that the patient is in some way responsible for their illness should never happen. When a patient becomes too ill to attend appointments they are totally ignored, no care for the severely bed bound. ME clinics need to be open to take part in research to progress treatment.</i>
<b>663</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>I was given options of therapy or CBT. I was bed bound with Post viral fatigue as a teenager. I know how it works and knew it had got worse now I'm in my 30s. Finally diagnosed after 18+ months. I do not need therapy (I have had before) but I am very positive that I have diagnosis on paper so I can now get support. I get PEM and CBT is not a viable treatment. There HAS to be a 3rd option of general support. Someone to check in and monitor, making sure we are reminded to log progress/issues. I look forward to reading the follow up on this</i>
<b>664</b>	Liverpool CFS/ME Management Services	<i>My GP said I should keep going and not give in to it!</i>
<b>665</b>	Not listed	-
<b>666</b>	Not listed	<i>There needs to be a lot more tests done on people with ME eg brain scans, mri and more help from the government regards to workplace, pip</i>
<b>667</b>	Not listed	<i>I hate tick box questionnaires, they can be misleading. Only by one to one interviews by a qualified professional. Those that have been studying CFS/ME over time, outside the accepted NHS guidelines.</i>
<b>668</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>PAY ATTENTION TO RESEARCH!!!</i>
<b>669</b>	Middlesborough - South Tees CFS/ME Service	<i>We need more funding, training and treatment for this debilitating illness. It is made worse for me by also having several types of dysautonomia including PoTS, fibromyalgia, MCAS, and chronic pain from a spinal and pelvic condition.</i>
<b>670</b>	York - Yorkshire Fatigue Clinic	<i>While the advice and help received from the fatigue clinic was excellent. I only received it after years of either not getting help or getting wrongly diagnosed by GPs. I had also seen a GP that refused to refer me to the clinic despite a recommendation from the hospital</i>

<b>671</b>	Liverpool CFS/ME Management Services	<i>I've had no help in the past 9 years besides a few weeks of CBT which was hopeless</i>
<b>672</b>	Leeds and West Yorkshire CFS/ME Service	<i>I asked for trial of HRT and this seems to be helpful.  I feel the GP thinks the specialist clinic is doing much more than it does. le clinic does nothing in the way of testing, or suggesting drugs or supplements that may help. So I felt that I fell between two stools.</i>
<b>673</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>There is hiatus for 16-18 yr olds in terms of specialist care. Due to lack of specialist consultants it's vital that GP's receive appropriate training with support from specialist nurses.</i>
<b>674</b>	Norfolk and Suffolk ME/CFS Service	<i>There is so much wrong with current advice it is a minefield for both practitioner and patient. Developing a baseline is all well and good but we also need the tools and sport necessary to have any quality of life. Powerchairs, stair lifts, seasonal checkups at home, all of these are necessary to maintain any semblance of normality.</i>
<b>675</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>I realise my recent experience of cbt at the Royal Free has been extremely fortunate. I have had cbt from another provider in the past which asked me to reframe my thinking and simply be more active and this perpetuated shame and self-doubt about my condition. As a result. I did not listen to my body and pace myself, did not rest or reduce activity when my symptoms became more severe, and eventually I experienced a severe relapse after 12 years in recovery ans I had to stop work. I think that provision of cbt was actively harmful to my health. Also, when I was well enough to work, I had to rest (reclining with legs elevated) outside working hours in order to sustain my basic working routine. At that time, I was offered graded exercise but did not have the energy to travel to the relevant clinic or complete activity diaries required. At that time (as with now) occupational therapy targeting graded activity would have been more relevant than exercise-orientated physio in helping me plan a sustainable and health promoting level of activity.</i>
<b>676</b>	Essex Chronic Fatigue Service	<i>The worst advice was actually from the doctor who just dismissed my symptoms and said dizziness wasnt a major symptom of cfs and that I had to agree to follow their structure if I wanted any help. Luckily the OT was more approachable. Was still dismissed after 4 sessions as I was deteriorating! Cant think of any other service that would discharge you for getting worse.</i>
<b>677</b>	Bristol CFS/ME Service for Adults	<i>all nhs me/cfs clinics should be closed down immediately and those whose health has been irreversibility worsened should fight for compensation. what is going on in these clinics should be widely exposed in the media - which won't be easy, with the science media centre. ME organizations need to remember that the illness is ME, myalgic encephalomyelitis. me/cfs and cfs/me are not recognised by the WHO - get back to ME only.</i>

<b>678</b>	Not listed	<i>As a health professional myself, it would be good to have more clear work place guides in place to help me cope with working in a hospital setting and the long hours abd shifts and have better understanding from oc health and management for practical support.</i>
<b>679</b>	Norfolk and Suffolk ME/CFS Service	<i>pacing doesnt work, clinics seem to be far behind on the newest research, and they dont generally offer any treatments just that condition sucks.</i>
<b>680</b>	Liverpool CFS/ME Management Services	<i>More support needs to be given to people with this condition. It is a life changing condition which affect not you but your family and friends. Patients need to be listened to instead of being told they are being negative. No one wants to feel like they do with this condition and want to get to a place where they are able to enjoy life.</i>
<b>681</b>	London - Royal Free London NHS Foundation Trust Fatigue Service	<i>Have been discharged from Clinic though still unwell. Clinic woefully underfunded. Massive periods of time without an appointment. Now feel completely abandoned with no answers.</i>
<b>682</b>	Not listed	<p><i>The guilt associated with being told 'if you do more you'll get better' is enormous. I was bed bound and in a terrible way... the energy required to get to appointments on the few occasions I could manage would set me back months. Then I'd feel guilty that I tried to go something I knew I couldn't do when my energy might have been better used laughing or enjoying my family.</i></p> <p><i>We do not want to be ill. We try everything to try to be better. I was ignored and struggled on with working with two under fives .. I should have had help. Instead I became very ill and I'm sure this made me weak so I now have 14 named autoimmune diseases.</i></p> <p><i>I believe ignorance and some sexism make some gps and consultants seem ignorant and uncaring. Please listen. I have not had any support or a health care for ME since 2005 as there is no service or consultant... this is ridiculous to have wasted my life for so long instead of enabling me to become s productive member of society.</i></p>
<b>683</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>The best help I got was privately not from the nhs whose support is not local and their process was to prove you don't have me/cfs rather than take symptoms seriously and use for eg depression as a way of not committing a diagnosis. Any services also need to be more patient facing . I work for the trust as a professional that assess me and the lack of help is reminiscent of everyone's experiences that this is treated like a second class illness due to lack of definitive diagnostic tests .</i>
<b>684</b>	Malvern - Worcestershire CFS/ME Service	<i>The service in Malvern have been invaluable to me. I feel they are hindered by certain things being out of their control. For example, I still haven't had my house evaluated for any aids I need, as that's with a different department. They need more funding to enable them to provide more care to more people.</i>

<b>685</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>We need biomedical based clinics not cbt and dangerous exercise.</i>
<b>686</b>	Not listed	<i>I am shocked at the lack of understanding regarding this condition. I am a sports coach and literally have no idea where I go from here with it.</i>
<b>687</b>	Aylesbury - Buckinghamshire Chronic Pain and Fatigue Management Services	<i>Please educate the general population and GPs. So little useful help out there and so much scepticism of this being a genuine illness. My daughters education has been severely damaged with no help from her (private) school whatsoever. She had such potential.....</i>
<b>688</b>	York - Yorkshire Fatigue Clinic	<i>The fatigue clinic taught me to carefully increase activities by only 10% and only once I had a stable baseline. They emphasised first and foremost the importance of good quality rest, not sitting and thinking about what you need to do. I believe [professional York Clinic] has a thorough and up to date understanding of the condition and recognises how important it is to do any increases safely and so the body does not feel an impact, rather than just 'pushing through'.</i>
<b>689</b>	Liverpool CFS/ME Management Services	<i>ME is a physical condition and should not be treated as a psychological condition. Patients should be encouraged to carry out sustainable activities, but not to increase beyond their limits or to do physical exercise which will cause PEM.</i>
<b>690</b>	Wells - Somerset CFS/ME Service	<i>The support was time limited. There is no ongoing support</i>
<b>691</b>	Not listed	<i>More research to find bio markers. Only then will we stop being doubted and abused by most of the medical world.</i>
<b>692</b>	Not listed	<i>Only that I wished it haven't taken four years ( I was one of the lucky ones others I met it had been 12years) to get to a CFS clinic and the groups. Definitely needs to be more awareness from GPs and understanding of the symptoms of CFS and what is required to diagnosis CFS. I bounced between GPS and even a rheumatologist back to GP who had personal experience of CFS before being properly diagnosed and sent to a specialist clinic.</i>
<b>693</b>	Fareham - South Coast Fatigue	<i>Please please help to educate more GPs on the symptoms of ME/CFS &amp; fund support organisations</i>
<b>694</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>To be able to get help when is needed as at the moment there isn't any one out there to help me at all.</i>

<b>695</b>	Bristol CFS/ME Service for Adults	<i>ME is a physiological condition. The symptoms are numerous. They are physically debilitating. Because of this you can experience depression on the same scale as a cancer patient. ME is not depression in itself. A good GP will never put it down to a psychological problem. Rest is Paramount to get any level of recovery. Some sufferers recover quicker than others. Not everyone suffers the same symptoms to the same degree. There is a broad spectrum</i>
<b>696</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>It's clear to me that services to people with ME vary considerably. I feel incredibly fortunate in having an incredibly supportive and knowledgeable specialist in the team at Truro and a brilliant GP, but I dread either of those two professionals moving on from their posts and having to explain my situation to someone who simply doesn't understand, or thinks I just need to try harder. It would be helpful to see more consistency in understanding of this illness.</i>
<b>697</b>	Nuneaton - Warwickshire CFS Service	<i>I was told to find a sustainable level and then increase extremely gradually.</i>
<b>698</b>	Portsmouth Chronic Fatigue Syndrome Service	<i>The appointment was for 3 consecutive days from 10-3 which I found too much and we were told there would be no further appointments after that. I was too ill to attend the 3rd one. And the Southampton clinic is now closed</i>
<b>699</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Until the constant threat of Child Protection measures is dealt with, the treatment of children with ME/CFS will never serve the interests of children.</i>
<b>700</b>	Not listed	<i>We desperately need Medical Drs specialising in ME/CFS who can look at ALL test results; spot patterns and prescribe appropriate medical treatments and of supplements etc.... since I first became ill 25 years ago I've never had the opportunity to consult with a Dr specialising in this field. The only prescription I've ever received was slow release salt tablets; and despite them having helped me 20years ago, my current GP will not prescribe them now the symptoms they were prescribed to alleviate have returned &amp; worsened.</i>
<b>701</b>	Haywards Heath - Sussex-wide CFS/ME Adult Service	<i>The care that ME patients receive from the NHS is unacceptable and dangerous. I have been made substantially worse due to not being advised to rest, by being advised to do a set amount of exercise which led to exhaustion and a substantial worsening of my health. My ME is severe and I doubt I will ever recover now.</i>
<b>702</b>	Not listed	<i>UK GP's need better training. I've lost hospital support and have very little GP support due to lack of knowledge.</i>
<b>703</b>	Essex Chronic Fatigue Service	<i>Being able to access an inpatient nhs service was invaluable! As I was really ill</i>
<b>704</b>	York - Yorkshire Fatigue Clinic	<i>GET needs to be stopped!</i>

<b>705</b>	Not listed	<i>The ME/CFS service provided in Belfast has been completely cut due to funding issues</i>
<b>706</b>	Leeds and West Yorkshire CFS/ME Service	<i>There is so much I could say (had ME for approx 30 years) but the main point regarding ME services is that at present they can only offer advice on helping to cope with living with this devastating illness, not treatments, like we have all come to expect from modern health care. It is outrageous that harmful and inappropriate "therapies" were used for so long and for some services to be psychiatrist led is absolutely ridiculous. It would be helpful to have a regular clinic appointment at a GP surgery or hospital to be able to speak to a doctor or nurse with knowledge and understanding of symptoms and be able to do blood tests/monitor long term.</i>
<b>707</b>	Bath Centre for Fatigue Services	<i>My experience in the ME service was disgusting. I left at the first opportunity. This clinic, like the Paediatric CFS Service (which my daughter was in), is awful. They are an embarrassment to the ME community as they promote the psychological theories and not the biomedical side. I cannot emphasise highly enough about disbanding this service, as I feel that when the biomedical side of ME is properly researched, that the NHS will be sued by hundreds of people who have been harmed within this service.</i>
<b>708</b>	Norfolk and Suffolk ME/CFS Service	<i>Please stop the CBT and exercise nonsense. It doesn't work. Speaking from personal experience, It makes people worse. If there isn't a treatment, fair enough, but don't let psychologists just make one up. It wouldn't be allowed to happen with any other condition. People with ME have enough problems without being given a rubbish 'treatment' and then being blamed when it fails and they get worse. It's an outrage.</i>
<b>709</b>	Bristol CFS/ME Service for Adults	<i>CBT might help your mood, but it's not going to make the body 'heal' from CFS! To be told that is as good as saying 'its all in your mind, it's not a real illness!'</i>
<b>710</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>The advice I was give I tended to just say 'yes' and ignore some of it as it wasn't helpful. Consultants in this department accused my mum of FII because she didn't agree with treatment. She had to go to my doctor, as she was so worried about me, to get me to stop doing GET as it was making me worse and it was getting very close to my exams.</i>
<b>711</b>	Manchester CFS/ME Service for Children and Young People	<i>Now under adult services at Salford and recieving much better advice and support.</i>
<b>712</b>	London - Uxbridge - Hillingdon CFS/ME Service	<i>just talking about the disease is woefully insufficient</i>
<b>713</b>	Oxfordshire CFS/ME Service	<i>GPs need better training and understanding of the illness too. It should be renamed more appropriately from CFS as the general perception is we're saying we're tired and 'we all get tired'</i>

<b>714</b>	Not listed	<i>The NHS Approach is hugely outdated and unhelpful. I have been Poorly for 30 years now and having attended the CFS Clinics they offer nothing &amp; if anytime poor advice, you're simply better off going alone!</i>
<b>715</b>	Leeds - Yorkshire Centre for Psychological Medicine inpatient care	<i>Was told only option was CBT. Refused it</i>
<b>716</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<i>Clinics cause so much suffering, way beyond how ill CBT and activity make you. They destroyed all my teenage years. I missed them all. I was improving once I ignored their advice but had to tell them I was following it because of the threats. I was marked as truant at school, it destroyed my home life. My mother left. My father had to quit work. We had to sell the home and now have nothing left. The clinic encouraged the school to keep educating me even though I couldn't manage and continued to decline. The clinic didn't back me up in court, the guardian ad litem opposed me and the judge opposed me. I improved to about 20% by having ignored the doctors, the court intervened and three weeks of stress caused decline to about 3%. It took me 4 years to get back to 10%, another 5% the year after but the clinic is responsible for not protecting me and encouraging all the things that caused me decline. I shall never forgive them. I was pushed into CBT. Managed two sessions that caused me to become bed bound at the start.</i>
<b>717</b>	London - University College Hospitals Children and young people's specialist adolescent services	<i>There is nothing useful for adults in our area - and we were discharged at age 18</i>
<b>718</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>Patients become very disheartened when they are blamed for not improving, and told that they want equipment such as wheelchairs or shower chairs to 'enable' them to be disabled rather than to conserve energy or keep them safe. Having other conditions such as POTS go unidentified and untreated for years prolongs the misery of symptoms which contributes to fatigue and the sense of failure. Having those symptoms attributed to psychological issues results in patients losing faith in doctors when they need them the most .</i>
<b>719</b>	Peterbrough - Cambridgeshire and Peterborough CSF/ME Service for Adults	<i>I was given very little advice, my M.E. diagnosis was confirmed, which was significant as it took 3 years to get a referral, but nothing was explained, I learned how to manage through trial and error</i>

<b>720</b>	Norfolk and Suffolk ME/CFS Service	<p><i>Its impossible to define Mild, Moderate, Severe or very Severe.</i></p> <p><i>The condition is not that consistent to measure.</i></p> <p><i>I get symptoms from across the 4 definitions depending on day to day activity. Mental or physical or both.</i></p>
<b>721</b>	Suffolk Specialist ME and CFS Service	<p><i>I feel that I have had no help at all... that I have been labelled ME/CFS and just get on with it. Without support I'm lost... I have no idea what to do, who to turn to, how to manage my symptoms and to top it all I have no evidence of being ill so cannot get PIP</i></p>
<b>722</b>	Bolton - Bury and Bolton CFS/ME Clinic	<p><i>Would of found it beneficial to see consultant once a year instead of having to go through the nurses if I need to see him and if I don't see him in the 12 months then I have to go back to my GP to be referred.</i></p>
<b>723</b>	Portsmouth Chronic Fatigue Syndrome Service	<p><i>Pushed so hard three week hospital stay, came away with paranoia, severe anxiety, intrusive thoughts harming self and others 100 daily, taken four years to dampen them daily but have never gone away. Feel mefical staff dont believe nor see, understand complexity of illness and situation, feel they dont believe, been forced to take part in therapies, had gp refuse to sign sick notes to get only source of mine and mother as carers household income as stated will not continue to issue sick notes unless participates in some form of therapy, feel health care issue severely compromised as totally housebound doctors want us to attend outpatient appointment which can cause not eating properly for months, ill in bed for month recovering, gp doesn't want to do house visits, a fight with each official as nobody believes....traumatised by disbelief and forced to exercise, made to feel not telling truth and like we are not working hard enough, not putting in effort, not making progress.....anybody would not wish this upon anybody, thecillness affects, heart, visual, digestive, neurological, muscular skeletal, nerves, muscle wastage, joints partial dislocating, a kud turned into a woman whilst totally housebound seven and half years sitting in same room 3m x 3m every day, darkened.....mum sold her house it cost £7k GBP to move six miles to get under specialist CFS/ME clinic which cant help. 21 year old girl sat housebound for seven and half years prisoner in her own body..</i></p>
<b>724</b>	Not listed	<p><i>The Molineux clinic does not actually show CFS affects people or the effects it can have. I was misdiagnosed with having RLS along with CFS and that it was all in my head. The clinic went along with this diagnosis even though I said I was in pain and the treatment in suitable.</i></p> <p><i>I have since been to a private clinic who have confirmed my illness as POTS, Fibromyalgia, CFS, BFS. Clinics should listen to patients more rather than just listing to so called professionals.</i></p>

<b>725</b>	Newcastle - North of Tyne CFS/ME Service	<i>Referral and eventual attendance at a specialist clinic was an extremely long, protracted and complicated process. Prior to attending the clinic I received utterly indifferent and ill informed treatment from my GP practice, exhausting and extensive testing at the hospital and supposed support through Talking Therapies where no person knew a single thing about ME and I was told that I needed to receive treatment for my 'low mood' as that could be the cause of all of my problems. It is vital that GPs in The UK receive consistent training and instruction on how to support patients with ME. The current advice is damaging to patients and creates vast variations in the care that patients receive during and immediately following their diagnosis resulting in levels of care where indifference is a very positive outcome.</i>
<b>726</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>At my level CBT, GET is dangerous. I should not have been dismissed, belittled and pushed beyond my boundaries. As a result I developed new symptoms with speech, swallowing and mobility.</i>

<p><b>727</b></p>	<p>Newcastle - North of Tyne CFS/ME Service</p>	<p><i>The health professionals involved were largely well-meaning but the BPS model being used was highly inappropriate. There were instances it was used in unsuitable circumstances, in fact the stock answer to any problem was to get used to the idea of doing something and build slowly. This included when I said I no longer felt safe to drive. "Get in the car and sit there, next time turn engine on and sit there, then drive around the block..." as if I was scared, not having neurological/autonomic symptoms that made me literally unsafe! The service also failed to signpost me to the local POTS specialist despite me exhibiting extreme symptoms of autonomic dysfunction every session (sweating when everyone else cold, unable to sit on chair feeling so dizzy and unwell). The CFS specialist who referred me to the management group should also have had me checked for POTS before sending me there. It should be routine as it's so common among us. Any services need to be much more focussed on the patient and able to refer them to any other specialists as needed to help get the best quality of life. Symptoms need to be paid attention to and not used as an excuse to gaslight us. Psychiatrists should not ever lead these services. The lead of the service I attended gave me an initial assessment before letting me on the course which felt abusive and manipulative.</i></p> <p><i>I pushed myself to attend nearly all the sessions. It is natural for desperate people to do so, however much things are framed as optional or a choice. I was concerned that if I didn't go it would mean I would be less likely to be given help in future, both within the NHS and for state or other benefits. I held out hope that something covered would prove useful. I was compliant and did all the planning and examining of my activity levels and tried to do as I was instructed. It may have appeared that I increased my activity slightly but I was getting worse and worse physically and cognitively. I felt more and more distressed by how unwell I felt when I attended. It would take me the two weeks between sessions to recover enough to go again. No-one was asking us how we were managing or checking we were not pushing too hard to attend. I never regained my previous levels of activity since attending. I basically stopped driving during the course. We were not encouraged to lie down during the course and our heart rate wasn't monitored. There was no discussion of our symptoms and helping us understand them, or how to manage them except from a psychological approach. I wanted to understand them biomedically. The course minimised my physical suffering and therefore caused me to do too much and decline in overall function and also caused emotional distress in many ways. I felt medically unsupported and alone in my fight to survive. It has undermined my trust in doctors generally. The level of denying what was in front of their faces and the illogical basis for the BPS view of the illness and the advice given was astounding. I am not sure what year I went but it was the second time the group had run at Newcastle. It was pre PACE trial but they were already rolling it out as if there was an evidence base. There certainly isn't now.</i></p> <p><i>I wrote them feedback after the course. It makes me cringe to read it now. Whilst I was critical of the lack of focus on physical health issues, I was also unable to see the course fully for what it was, having spent over three months in attendance. This is why self reported follow up questions are not reliable. Until more time had passed I could not know the full impact on my physically and that I would not regain my previous levels of function, however limited they were. I was also caught up in the relationships with the professionals and could not clearly see that however much they believed what they were saying, and wanted to help, it didn't make it actually valuable. We are vulnerable</i></p>
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		<i>people who need to be treated with a much more credible approach, listened to, have symptoms investigated, be checked up on and given the chance to access things that may not be traditionally offered on the NHS such as soft tissue massage/ osteopathic which has been the best thing for me in pain management. We should have our level of disability properly measured and be offered support, aids and services as appropriate.</i>
<b>728</b>	Edinburgh - Lothian CFS/ME Service	<i>At one of the sessions, the psychologist said that she didn't understand why I felt the way I did about something I was experiencing and was very dismissive. At the next appointment, a month or six weeks later she said she had had a think about what I had said and apologised for her response. The time in between was a really hard time for me due to the initial situation and then being completely misunderstood. The number of sessions were not extended to take this into account and thus some of the advice and help promised initially was forthcoming because it took two sessions to repair the damage. It turned something which was supposed to be helpful into a very emotionally draining experience.</i>
<b>729</b>	Bristol CFS/ME Service for Adults	<i>The service I received was not harmful, it was patient and understanding. It encouraged me to hold boundaries for my energy and to pace myself, with careful increases when it felt possible. However there were lots of things that I've found elsewhere that were more useful (heart rate monitors). And being placed in groups with people at a similar level might have been more helpful. It was also hard for me to get appointments. Huge waits and I kept not getting my appointments for the nutritionist. And I just wasn't told what the actual affects were on body or given any hope. It felt like they weren't saying so much and instead I was having to read research from the internet.</i>
<b>730</b>	Bristol CFS/ME Service for Adults	<i>Opportunity to get back in touch or be seen every so often (even of only annually or every six months). The course I attended was very helpful but it was made clear that we'd been taught everything and there wasn't any more they could offer.</i>
<b>731</b>	Not listed	<i>Even though learning to pace and manage my illness better since going to the M.E/cfs clinic it has taken between 12-10 years of following the plan to get to the level I'm at now . Which is still not enough to get me back into work. I would like them to remember everyone is different in there recovery some are faster overs slower and some not at all. It is down to the illness not what individuals do or dont do.</i>
<b>732</b>	Harrogate CFS Service	<i>gp and health professionals better understanding of this illness. especially in older people. just because we dont ask for an appointment with gp doesn't mean we are well. could mean we cannot get to surgery as no energy.</i>
<b>733</b>	Cambridge and Peterborough CFS/ME service for Children and Young People	<i>They need to keep more up to date with research findings. I should not know more than them, especially as there is so little they can offer.</i>
<b>734</b>	Liverpool CFS/ME Management Services	<i>We need more biomedical research. I'm still severely ill even though I have done everything they have told me to do. It's as if they just wash their hands of us when we don't get better</i>

<b>735</b>	Bristol CFS/ME Service for Adults	<i>Me services need to be adapted to help those who have extra responsibilities and care needs. More specialists need to be available in Croydon. I have asked for referrals for 2 years to no avail</i>
<b>736</b>	Fareham - South Coast Fatigue	<i>While at uni there was a fatigue clinic I was referred to for 6 months. 6 months for a chronic illness isn't a long time as the recovery is very slow. It needs to be ongoing support. When I moved back home to Northamptonshire there was no clinic available, no specialists and my GP admitted not knowing who could support me. There needs to be clinics available throughout the UK so it's not a postcode lottery.</i>
<b>737</b>	Norfolk and Suffolk ME/CFS Service	<i>I was not deconditioned at acute onset 17 years ago. I was admitted to hospital with suspected brain haemorrhage at the time. Rest gradually improved the devastating and debilitating symptoms. However GET advised by a neurologist after discharge caused a severe relapse six months later. I've had severe relapses over the years all caused by physically overdoing it ..... due to my zest and former vitality in life I kept 'pushing it'. To the point of another but this time extremely severe relapse three years ago. I had to attend a Stroke Clinic, it wasn't a stroke but severe relapse of ME so I was discharged. That specialist clinic was fantastic for patients ..... speech therapists, dietitians, physios, doctors, OTs, specialist nurses ..... I long for the day when ME patients have access to such specialist centres.</i>
<b>738</b>	Edinburgh - Lothian CFS/ME Service	<i>The physiotherapist was well informed and the psychologist was understanding. Both gave good advice and useful tools to help me manage the illness. They offered a good service within the existing confines/limits of little research and lack of treatment of ME/CFS. I felt they understood what I was experiencing and were very supportive. However, because the service exists in the Department of Psychology, this gives entirely the wrong impression to anyone outside the necessary understanding of the illness. Both the physiotherapist and psychologist were clear in their understanding that this illness is physical.</i>
<b>739</b>	Bristol CFS/ME Service for Adults	<i>C.b.t and g.e.t. are totally inappropriate</i>
<b>740</b>	Norfolk and Suffolk ME/CFS Service	<i>Support is currently inadequate. Some of my peers require day to day help with basics. Auto entitlement to benefits should be considered.</i>
<b>741</b>	Not listed	<i>My work occupational health doctor [redacted] always gave the best advice and provided the best support and care. When she retired there was no adequate replacement and my condition deteriorated. I ended up losing one job but was given a downgraded less stressful job but 10k less pay.</i>
<b>742</b>	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<i>I would like more GPs and consultants to be made aware of the symptoms of ME/CFS and not to make people feel like it's all in their mind and made to feel like liar's.</i>

<p><b>743</b></p>	<p>Bath Centre for Fatigue Services</p>	<p><i>I think a lot of positive outcomes at CFS clinics are due to people feeling relieved and validated to finally have a diagnosis, and to have some kind of treatment, rather than as a direct result of any sessions they attend. I'm sure that true of my depression/fatigue questionnaires.</i></p> <p><i>I certainly didn't get a clear message about the dangers of exceeding my energy levels in terms of the wide ranging and often severe physical implications, and have now deteriorated. There was a lot of 'be kind to yourself' but very little hard factual information about the physiological symptoms and impacts.</i></p> <p><i>There is not sufficient focus on understanding the full range of physical symptoms (Ramsey ME) and how to listen to these as warning signals to prevent pushing too far and causing painful PEM episodes. I am still only understanding them myself, and discovering that various things are actually ME-related.</i></p> <p><i>I recently had additional 1-2-1 psychology sessions, which helped to disentangle some work related stress, after a few months absence from work. However I learned a lot about ME through online research during that time, and was incredulous and frustrated that the staff i saw did not know about original ME history or recent research and relied on NICE guidance. I would've hoped a 'specialist' clinic/staff would have been more pro-active in maintaining in-depth and up to date knowledge.</i></p>
<p><b>744</b></p>	<p>Bristol CFS/ME Service for Adults</p>	<p><i>To summarise my experience:</i></p> <ol style="list-style-type: none"> <li><i>1. ineffective and misleading assessment tools (questionnaires and interview) that did not appear to capture my poor level of functioning</i></li> <li><i>2. inappropriate advice and recommendations for my level of functioning</i></li> <li><i>3. unhelpful and confusing information/materials that did not match my experience of illness and pacing</i></li> <li><i>4. lack of useful or appropriate support and information to manage life with a long term debilitating condition</i></li> </ol> <p><i>NB Please note I was not offered either CBT or GET and yet my experience was still dire (due to the system or set up rather than individual staff)</i></p>

*I found these close option answers hard to answer, eg I was given advice on activity mgt, BUT the advice given was inappropriate and caused me harm, etc.*

*There is such a paucity of support for ME patients that I sometimes feel that 'anything is better than nothing', but the misadvice given by the ME/CFS Unit was so harmful that these units do need to be dissolved.*

*Alternatively, they should operate under the direction of the ME Association and give out advice and support to patients based on factual evidence-based scientific research, not just whatever the particular belief is of the individual who works there as to what ME 'might' be, (in light of nothing else to disprove this persons opinion and the vacuum of scientific research).*

*In the Northeast of England we have a lack of ME specialist consultants, so that GPs are misdiagnosing ME/CFS. Two ME specialist consultants I have spoken to in the past said that in 50% of the referrals they are sent by GPs where the GP had diagnosed ME/CFS, they find that when they see the patient, it is not ME/CFS, but a different cause of the problem. GPs should not be expected to diagnose a complex condition like CFS/ME for which there are no easy blood tests; symptoms are similar to many other possible illnesses, etc. We need to start reform of NHS provision from the top, ie ME needs its own medical specialism.*

*I have been lucky enough to see 3 different ME consultants who have all confirmed my ME diagnosis, but then all offered a different root cause for ME (which since minimum research is being completed, they are free to propose whatever cause they want for ME). This is completely misleading for the patient, eg the consultant who diagnosed me with ME who worked in cardio vascular specialism told me that my ME was all caused by problems in my BP control, the consultant who worked in rheumatology told me my ME is will most likely be found to be an auto immune condition in the future, and the consultant who said I had ME who worked in Tropical Medicine said my ME was most likely caused by an as yet unknown virus in my body and was similar to an HIV infection.*

*How can this the current structure be maintained where consultants who diagnose ME can come from ANY discipline 'who just happen to have a bit of a research interest in fatigue?' It feels like they are doing us a 'favour' by diagnosing us as 'not part of their 'day job'. ME needs its own professional medical discipline, or to sit under the SAME UK wide discipline based on most likely cause based on the biomedical scientific research so far. It is far too haphazard at moment. Would this be tolerated in any other disease, eg MS (with far fewer patients in UK)*

*When we look at all the scientific research that has come out in the past 10 years which shows measurable abnormalities in how the human body functions differently to others in people with ME, I feels like the ME/CFS units and past NICE guidelines are in a 'time delay' where provision of services is still based on outdated and disproved theories from the 1980 'Yuppie Flu' era. We are ignoring the wealth of scientific information that's been published worldwide in recent years to say that genuine ME is a biochemical issue within the human body.*

*As an acid test of the validity of these psychological theories, surely after 30 years of application, wouldn't there be far more ME patients saying they'd been helped or cured by utilisation of these psychological approaches?*

*Biochemical research can't provide a cure at the moment (partly as been so underinvested in research into this area in past), but it can show there are measurable differences in people with ME, so that's where all the funding*

		<p>needs to go, to expand this field of research and lead to some clues towards a future treatment.</p> <p>I speak as somebody who had was a Senior Lecturer at a University until 2011 when my ME became so bad that I lost my career, my house (as could no longer live independently), my friends, my love of mountain climbing, caving, hiking and sailing, and now EXIST on state benefits housebound and often bedbound. I feel 'invisible' and let down by an NHS that I had previously thought was there to help me when I was ill, vulnerable, and unable to help myself. We need funding into biochemical research to be diverted from operating the existing ME/CFS Units and also new research money invested. I do NOT need more kind words of hope and sympathy which are then not followed up by action.</p>
<b>746</b>	Exeter, East, Mid and North Devon CFS/ME Service	<p>The biggest problem with the Exeter ME clinic is that they cover a large geographic area and only see patients in Exeter. I live an hour's drive away and haven't been able to go to Exeter at all for several years. Driving an hour each way to attend a 2-hour group session is so far, far above the level of activity I've been capable of for the last few years that it's ludicrous to suggest that it might help me! They are also very difficult to contact on the phone and not set up for helping people over the phone. I was eventually discharged because I "missed" a phone appointment despite sitting in bed all day waiting for their call.</p> <p>I have had ME for over 20 years and have had contact with two ME clinics (Wareham and Exeter) and numerous mental health services and OT services, and the vast majority of medical professionals I have met have been worse than useless, and some have been very damaging. My best experiences have generally been with Occupational Therapists and my worst experiences with consultants and psychiatrists.</p>
<b>747</b>	Exeter, East, Mid and North Devon CFS/ME Service	<p>I felt very let down by the service due to being dismissed when I was struggling the most. Being diagnosed with Mental Health conditions, which were brought on by my deterioration in my M.E/CFS over the years, losing many aspects of my life such as giving up work and volunteering, splitting with my husband, the death of loved ones etc. I have found many others like myself suffering from M.E/CFS and later have Mental Health problems such as Depression, Anxiety, Agoraphobia. However, I do feel the M.E/CFS Service did not handle this very well. I no longer get any help with my M.E/CFS despite struggling. I would advise the Mental Health aspect to be taken into account for further treatment of M.E/CFS patients in the future.</p>
<b>748</b>	Llanfairfechan - Betsi Cadwaladr University Health Board West CFS Service	<p>Ongoing support essential</p>
<b>749</b>	Manchester CFS/ME Service for Children and Young People	<p>Physio made my daughter worse. Shaking and causing PEM. So much conflicting advice. The professionals don't even know what to do. How are we supposed to know. Hoping NICE really take on board our personal views.</p>

<b>750</b>	Bristol CFS/ME Service for Adults	<i>CFS services were an absolute joke and disgrace, they did not understand the basics and failed to listen</i>
<b>751</b>	Not listed	<i>There are possible devices worn on the wrist now which can determine when you should rest. There are some drug treatments, FMT, blood replacement which could be discussed patient by patient and have more of an evidence base than GET and CBT. There are specialist centers in other countries we could look to. CBT used something called artist's chair for pain management - this is the only thing I've retained. It has never treated my ME/CFS which is now significantly worse. I am now only told I'm sorry there's nothing I can do by my GP. I struggle to get access to benefits but can't work, have no treatments and no prospect of any treatment on the NHS. I look to ME action and the Open Medicine Foundation for support and research updates and hope. Someone who I went to uni with got sick at the same time. She rested and I didn't. She is better and I am worse. I hear this all the time.</i>
<b>752</b>	Oxfordshire CFS/ME Service	<i>Why are we still answering questions about CBT and GET? Surely by now you understand they are not, and have never been, appropriate forms of treatment. Why make us waste the little energy we have on this? Why not ask us about other forms of treatment we need such as help with bladder issues, stomach issues, orthostatic issues, pain management, pacing strategies, helpful aids at home, getting around, etc. etc. Why is it desired that this is the answer when it clearly isn't? A strategy was put in place, it failed, it's time to change the strategy. Please help us. We have waited too long. Thank you.</i>
<b>753</b>	Leeds and West Yorkshire CFS/ME Service	<i>In 2018 the OT wanted to refer me into hospital, as they said I needed more intence input that I could get at home. I looked into the treatment that the hospital offered for ME, which were GET and CBT, so I wrote back to the OT and explained I did not feel these were the right treatment for me, use to the worried around there effectiveness and that NICE was in the process of reviewing them and asked for some other treatment or help, there responce was to discharge me.</i>
<b>754</b>	Manchester CFS/ME Service for Children and Young People	<i>It is a shame that the clinic is not accessible for my daughter due to it's distance from our home, as we haven't really fully been able to access the services the clinic may provide. Some of the literate that was put in a folder for my daughter was dubious, saying it was all in the mind, I questioned this and took that bit out the folder when we got home!</i>
<b>755</b>	Private clinic	<i>I was offered GET from an NHS consultant and nutritional advise with pathological disease tests by a private clinic. With the GET from the NHS consultant I made a partial recovery but I believe this was only because I was taking herbal stimulants at the time of doing the GET. However after a general anesthetic for a minor operation my body crashed and I never recovered my ability to exercise even when taking the stimulants which I have since discontinued.</i>
<b>756</b>	Bishop Aukland - Durham & Darlington CFS/ME Service	<i>Tried CBT outside the clinic twice. Neither person had an understanding of ME/CFS to understand why I couldn't process or read set tasks. It was too goal driven. One person was suggested if I change my thinking, physical symptoms would improve. I immediately stopped treatment with agreement of my GP.</i>

<b>757</b>	Bristol CFS/ME Service for Adults	<i> pacing was helpful to help you understand the illness, energy levels or lack of, managing things differently, adapting how you do things. The awareness day at broadgreen hospital , that was planned , didn't get enough patient input , wasted opportunity . There needs to be more awareness, understanding , of ME and patient input into the NHS of how ME affects us as , over the past five years and counting of having this chronic illness, I don't feel there's enough understanding at all. My GP surgery I first saw when I got ill, didn't really listen affectively to how ill I was, instead of looking at the overall picture of all my symptoms , doctors only look at some , I was referred to different consultants for headaches, rheumatology, etc , I feel they don't talk to each other , it takes far to long for patients to be referred to ME clinics , it did in my case, It puts more unwarranted stress on the patient to wait that long . To get the proper asesments they need , the quicker it gets done the better. . When your discharged from Broadgreen, there should be some sort of follow up or aftercare maybe, your left to your own devises. Also more information should be given about aids in the home, ways to apply for wheelchairs , blue badge, etc I have only just learnt about these things , it would have helped me a great deal when I first got ill.</i>
<b>758</b>	Liverpool CFS/ME Management Services	<i>Please treat this medical condition with the seriousness, attention, care and funding it deserves. Scrap GET. Educate health professionals. Invest in research. Thank you.</i>
<b>759</b>	Bristol CFS/ME Service for Adults	<i>I found that rigorous pacing from a low basellne of activity worked for me</i>
<b>760</b>	Bath Specialist Paediatric CFS/ME Treatment Service	<i>the CBT and GET approaches miss the main areas of symptom improvement which for me have included amitriptyline for good sleep and steroids to correct cortisol imbalance. neither were mentioned or offered through specialist ME/CFS clinic yet both are known to co-exist with CFS/ME. Focus is too heavily on psychological aspects of disease not biological</i>
<b>761</b>	York - Yorkshire Fatigue Clinic	<i>Just getting to the clinic made me terrible ill and completely shattered.</i>
<b>762</b>	Not listed	<i>Some questions needed a descriptive rather than yes / no / don't know option please.....</i>
<b>763</b>	Leeds and West Yorkshire CFS/ME Service	<i>This was the first of 3 different clinics I experienced. My main problem was understanding that doing anything at all was 'too much': (I was diagnosed as moderate to severe and I had to learn that just getting up uses up most of my energy.)</i>
<b>764</b>	Oxfordshire CFS/ME Service	<i>Listening to my body is key and only progress to doing more when able. PACING is not a cure but helps manage symptoms and I think if I was taught this when I first spoke with doctor I would not have kept pushing through and deteriorating. More insight is needed in the other symptoms, cognitive dysfunction, sensory overload, (light, sound, touch, smell) and orthostatic intolerance which can be just as debilitating. I have not given up and I m not some who enjoys lazing around.</i>

<b>765</b>	London - University College Hospitals Children and young people's specialist adolescent services	<i>We went once and never went again they were so bad. Her name was [redacted] (something). Completely useless and clearly didn't listen as her notes from the meeting were highly inaccurate! I emailed her and our paediatrician and GP. She sort of apologised but we lost faith in conventional medicine at this point and discontinued. Have been managing it ourselves and with alternative therapies since. Good progress initially after LP but then a relapse and back to where we were a year ago - fatigued housebound in pain with memory fog gastro issues and constant nausea. Feel we have been entirely forgotten about by the medical world and nowhere for us to turn to.</i>
<b>766</b>	Middlesborough - South Tees CFS/ME Service	<i>This service was piecemeal and disjointed: 'excellent in parts' but overall unsatisfactory. I was given a follow-up appt 6 months in advance which I forgot. I was discharged from the service for not attending, it being assumed that I was better and no longer needed the service. Brain fog being a key symptom, you'd think a specialist service would understand!</i>
<b>767</b>	York - Yorkshire Fatigue Clinic	<i>The advice I was given helped me understand more about the biology of the illness and how I need to take care of my body in order to manage my illness. I'm sure there were elements of CBT within the consultations, but nothing overt, and nothing which implied I was falsely imagining my illness. I was given a good framework to manage the fluctuations of this illness.</i>
<b>768</b>	Bristol CFS/ME Service for Adults	<i>The staff were very arrogant. They said they knew all about ME (not that they called it ME) and that I, a mere patient, knew nothing. In reality, it was them that knew nothing. Terrible clinic. Terrible staff. Please warn others.</i>
<b>769</b>	Salford CFS/ME Service	<i>Please remove graded exercise therapy from your recommendations. It is dangerous and I had to quit my jobs months after undergoing it as my condition worsened. I personally do not think physiotherapists are an appropriate choice for treating people with ME/CFS.</i>
<b>770</b>	Torquay - Torbay and South Devon CFS/ME	<i>I was told I have very severe CFS and could not attend any sessions. The Dr warned me I could end up in hospital being turned and fed if I pushed myself. They did recommend a PA tho which I now have for 3 hrs a day and is invaluable.</i>
<b>771</b>	Oxfordshire CFS/ME Service	<i>training needs to make it clear to practitioners that treatment should be adapted to individuals both in terms of content and communication and content. Content because what works best varies a lot between sufferers and communication because getting the style of this wrong can cause significant psychological distress, compounding the problems of the patient</i>
<b>772</b>	Liverpool CFS/ME Management Services	<i>Not really, although I had heard of medication being used in the US that the Consultant who diagnosed CFS at the Royal Liverpool had not heard of but said he would look in to but my own GP just was not interested.</i>

<b>773</b>	Edinburgh - Lothian CFS/ME Service	<p><i>The healthcare professionals involved in my care were a psychologist and physiotherapist at the group clinic I attended. They strongly emphasized that although the clinic is in psychology dept they considered it a medical/physical disease and they were there to help us manage non-medical issues related to the disease. I found it extremely helpful the focus on rest and actually doing less and alot of "only if you feel ready" to do more. It has made me feel that had I been given this advice from the outset and not forced myself into overactivity that perhaps my disease may not have progressed, it was a sentiment expressed by others who have had the disease for much longer than I have.</i></p> <p><i>They did a great job with the resources they have been given to work with by NHS/govt, but I feel not having any medical input is just reinforcing the belief that ME is psychological rather than biomedical. Other than my initial GP appointments when I had blood taken and then was diagnosed, I have no medical or specialist involvement in relation to my ME and physical symptoms, I feel its a case of "you are on your own now".</i></p>
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<p><b>774</b></p>	<p>Not listed</p>	<p><i>The advice I was given has varied enormously from place to place. I've moved house between 4 different counties since 2004 when I fell ill.</i></p> <p><i>The only specialist clinic I was sent to was purely for physiotherapy (Essex, 2007). Which I wasn't able to continue due to ill health. I rang a few times, putting off appointments, saying I was too ill to attend. I wasn't offered any alternative to the regime I'd been given. In the end they curtly told me I was no longer on the programme and would have to re apply through my GP if I wanted to be treated. I was in tears. And ill.</i></p> <p><i>In two places I was given advice that was helpful in varying degrees but neither was through a specialist clinic.</i></p> <p><i>The first helpful advice was my GP who had had the condition herself and first diagnosed me when I didn't recover after having shingles (Cheshire, 2004). The advice was, "You probably have an ME-like condition. That means you are like a leaky boat and need to keep the load light so you can stay afloat." That was helpful to a certain extent. At least I had a sort of diagnosis and permission to be careful. No specifics about rest, or exercise, or CBT were mentioned.</i></p> <p><i>The second helpful advice was through a CBT referral at another GPs (Essex, 2011) My therapist had been a nurse before and concentrated mainly on helping me find my base-line sustainable level of activity. This was helpful and took 3 months to work out. I've continued carefully pacing myself since. That is the BEST advice I've had. The rest of the CBT work (psychological approach) was helpful in other respects in my life and helped me learn to cope with living with ME/CFS without getting depressed. Also in Essex, (2012) I had help when I was referred to an "Expert Patient Programme." This gave me confidence to look after myself - especially ensuring I get sufficient rest (pace myself) and to explore internet sites (though that wasn't explicitly mentioned or encouraged) and some tools to help when things got really bad. Actually, meeting with others was helpful in itself. The isolation, brought on by a debilitating condition, exacerbated by not having anyone who understands, is awful.</i></p> <p><i>When I told my current GP my history and approach to managing, she simply said, "Well, you know more about it than me. Just don't overdose on supplements or do anything wacky or expensive from the internet." End of consultation (Suffolk, 2019).</i></p> <p><i>It's confusing to be treated so differently in different places. It has eroded my confidence and trust in the medical profession. In one place I never even told my GP about this condition - I couldn't see the point (I was there for 2 years). I've ended up resorting to filtering out sensible advice and support on the internet and self treatment with pacing, many supplements, amino acids, and changing my diet.</i></p>
<p><b>775</b></p>	<p>Bristol CFS/ME Service for Adults</p>	<p><i>Yes: combination of B&amp;C on previous question: to increase activity very cautiously where possible, retreat if symptoms worsened before trying again AND be aware that the will likely be new limits within which you must work to avoid much worse relapse.</i></p>

<b>776</b>	Plymouth Sentinel CFS/ME Service	<i>Having tried GET previously and it making me crash, there was too much emphasis on being able to get back to near normal activity levels, I do believe that we can sometimes increase levels but it is important to understand that activity in this context should include all activity (i.e. cognitive/emotional) not just physical. This was mentioned in triggers but was disregarded with advice around increasing activity. There was also not enough emphasis on increasing when you are able (sometimes can be months, certainly not week on week) or understanding your own personal limits, as I have found that just by increasing a small amount when I thought I was ok, that I have ended up bedbound for months. Also treatment is aimed at mild sufferers, when I was moderate I couldn't have attended and the advice would have felt meaningless. There needs to be more tailored support for moderate and severe sufferers.</i>
<b>777</b>	Gillingham - Kent CFS/ME Service	<i>Since 2009 I have not received ANY informed expert advice or support with my ME and have encountered disbelief and hostility.</i>
<b>778</b>	Leicester CFS Service	<i>I declined help as felt what they offered was counter productive. It also felt like a waste of precious resources for those that desperately need mental health services.</i>
<b>779</b>	Bristol CFS/ME Service for Adults	<i>I attended a satellite service of the Bristol clinic, the person I saw was lovely and helpful but the referral is really short (6 sessions), the materials provided are very superficial and somewhat contradictory and not terribly supportive in tone. I could have done with a more in-depth service and more frequent medical contact to allow discussion of symptoms as they changed and more ongoing support. I also have a great GP but she has a very limited and outdated knowledge of ME/CFS.</i>
<b>780</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<p><i>GP's and their practices should have ME/CFS training, as once discharged from an ME/CFS Clinic we are returned to their care. As a patient I should be able to have confidence that any Dr or Nurse within the NHS has actually had training on this illness, and that at a minimum it is understood that it causes dysregulation of the whole body.</i></p> <p><i>There should at least be an annual follow up after being discharged back to the GP. What is their remit on follow-up? We are not in remission when discharged from the ME/CFS Clinic. Many sufferers do not go back to their GP because of their lack of knowledge, actual treatment or monitoring tests. It doesn't mean the individual is better, back at work or participating in life. It means we are forgotten. Follow-up statistics and data are important to ensure we can get proper treatment in the future, especially with the fluctuations of the illness.</i></p> <p><i>Some blood tests available privately eg: Acumen ATP/ADP efficiency etc, should be made available to the NHS. For such a large group of patients, there is STILL so much ignorance of this illness within the NHS, as symptoms often crossover several departments. This is reinforced by there not being a department that ME is officially under within the NHS; no proper tests, bio-markers or treatments available other than GET that can cause accelerate the illness, and "coping strategies". These "treatments" would be go hand in hand with proper treatment for other chronic illness groups.</i></p> <p><i>The majority of individuals I have dealt with, within the NHS, have been kind and want to understand the complexities of the symptoms and the impact on</i></p>

		<i>a daily basis .... but I shouldn't need to use part of my limited daily energy explaining the illness first to healthcare professionals.</i>
<b>781</b>	Newcastle - North of Tyne CFS/ME Service	<i>It would be very helpful if the health professionals involved would keep up to date with current research. An understanding of the underlying pathology would lead to better treatment and outcomes.</i>
<b>782</b>	Edinburgh - Lothian CFS/ME Service	<i>help us 27years. experiance ME</i>
<b>783</b>	London - Royal London Hospital for Integrated Medicine CFS Service	<i>Since moving back to Scotland, on the advice of Consultant, for palliative care, I have had no help whatsoever. I tell my doctor what I need as she doesn't have a clue - she admits, I know this disease better than her.</i>
<b>784</b>	Oxfordshire CFS/ME Service	<i>Overall I have received a poor service especially from male medics. My symptoms were also similar to autoimmune diseases with regular vasculitis leg rash and haematuria. A female GP diagnosed Henoch Schonlein Purpura in 2018 and I now have an annual renal review. I'm not sure if ME or HSP is the underlying cause for gut problems.</i>
<b>785</b>	Grantham - Lincolnshire CFS/ME Service	<i>Need more funding for research. Because ME.CFS is not seen as a critical issue IMO. Keep up the great work you do. [redacted].</i>
<b>786</b>	Stockport CFS/ME Service	<i>The nurse I had is exactly the type of person everyone with ME should have access to in the UK. That both the clinic itself and NHS guidelines worked against this arrangement is horrifying to me. I've lost my most valuable support point in life, the clinic has lost a nurse who was genuinely caring and excellent at her job. The NHS is managing the clinic in what I would personally say is the exact opposite of what many patients require. There are some who need long term support - not constant home visits, just occasional ones to catch up and help make further assessments about what might be helpful to them. The NHS really desperately needs to accept that such patients do exist and not treat us all as one giant group who share needs that can be met by 6 visits and the offer of 'treatments' which even the staff will eventually admit they held little hope would be beneficial. Good practitioners need NOT to be driven out of this area. I can't stress that enough as they're so incredibly rare!</i>
<b>787</b>	Romford - Queens Hospital National CFS Diagnostic and Specialist Rehabilitation Service	<i>no ongoing support or support for pain/cognitive issues are available.</i>
<b>788</b>	Dorchester - Dorset Children and Young People's Chronic Fatigue Service	<i>Knowledge in schools for teachers, specialist nurse gp training, so I can see someone local to me.</i>

789	Truro - Cornwall & Isles of Scilly CFS/ME Service.	<p><i>When I was first diagnosed the knowledge and services were poor. I was a single mum of two young boys.</i></p> <p><i>No signposting to agencies for practical help. I was worried my children would have to go into care.</i></p> <p><i>The doctors just give you drugs which often made me worse.</i></p> <p><i>Social Services knew nothing about the illness, came out to see me, told me I was depressed and never came back.</i></p> <p><i>The service was poor.</i></p> <p><i>The only good help was from a specialist O.T. who helped with pacing. But I still felt under pressure to do things beyond my capabilities.</i></p> <p><i>If I had had more help (Nutrition advice, practical help with the children, DLA (I was refused for years and didn't have the energy to appeal), and better mental and emotional support) in the early years, I would have got better much quicker.</i></p>
790	Maidstone - Kent & Medway CFS/ME Service	<p><i>belief. Belief. Belief. Fatigue is a broad umbrella. There are as many avenues to get in as there are to get out.</i></p> <p><i>Intelligence is needed. Intelligence beyond the textbook. Look at the personality, the drive, the dynamism and the courage of the person BEFORE they got ill. People do not change their personality.</i></p> <p><i>first do no harm.</i></p> <p><i>My suffering has been intensified 100% because of the disrespect and disbelief. It is pure to my own stamina and resolve that I haven't killed myself.</i></p> <p><i>My sisters website is : [redacted]. As a family of high achieving professionals we have lived 67years with this pernicious physical illness. We are in the broad umbrella that is "ME/Fatigue". Get in touch. We have more balanced mental and physical expertise than anyone on your panel.</i></p>
791	Surrey - South West London and Surrey Chronic Fatigue Service	<p><i>I only managed the 1st day. In a wheel chair with my husband, after a long wait a large group were shown into a room to watch and listen to a film. Meanwhile there was drilling going on outside. My husband wheeled me out after 5 minutes as I am light and sound sensitive. He took me home. It took me 3 weeks to recover. There was no option for a phone or Skype consultation.</i></p> <p><i>Prior to this it took 16 years to be diagnosed, despite endless tests. Eventually a GP in Kent where I was then living, the neurologist where he referred me and a psychiatrist in SLAM diagnosed me with ME therefore somatisation! I have no mental health problems. Now unresolved issues. I am now registered as having severe M.E/CFS</i></p>
792	Bristol CFS/ME Service for Adults	<p><i>Yes, I have had two different experiences with the M&amp;E services. The ones I refer to here we're on first encountering the service and getting advice at that time. This was very positive for me in understanding and managing my condition. The answers in this survey do not pertain to later experiences with the clinic. For example follow up sessions a couple of years later and subsequent phone backup sessions. It indicates that I should do a separate survey covering this period of time.</i></p>

<b>793</b>	London - King's College London and South London & Maudsley Chronic Fatigue Service for children and adolescents	<i>the hospital consultant had me repeating blood tests every month for nearly 2 years to then turn around and tell me to "pull myself together". I would have preferred he told me he did not know what was causing some of the results found in my blood test and offer to see me on a less regular basis and ask my GP to keep an eye on me. I later found out there was a Professor from an ME/CFS organisation who was on secondment to this consultants clinics but as the felt ME/CFS wasn't a real condition I was not referred to the Professor. Had it not been for my GPs determination to help me find a way to manage day to day I would not be where I am now. My GP offered help as and when I needed it - sometimes just calling me or asking me to pop in and see him/her for a chat. I was never made to feel that my condition was "fake", in fact, my GPs treated my condition as a challenge they wanted to help support me manage. I felt it was essential to have one healthcare professional understand that although I looked healthy I did not feel that way - if you slept for 22 hours a day you would like good too. I have accepted that my health causes me to adapt every aspect of my life - from when I sleep, what smells, sounds and light I can tolerate etc. It would be very helpful if the NHS "experts", consultants etc and DWP staff would be compassionate and considerate when they encountered anyone with our conditions</i>
<b>794</b>	Exeter, East, Mid and North Devon CFS/ME Service	<i>its been a long time since I went to a clinic and part of that is moving away from Exeter and doctors telling me there isn't one around and for clinics to say there is nothing else they can do/help with after you have been to all the courses, you kind of get left to it with no follow ups and to just call back if things get worse and then sit on a list for months on end again... which has been the hardest thing for me to deal with as they are not around when you need them and you don't have continued follow up meetings so is hard when you try to apply for pip or other benefits as all my consultant letters are so old that they don't want to accept them... but nothing has changed with my condition so a consultant can't help.</i>
<b>795</b>	London - King's College London and South London & Maudsley Persistent Physical Symptoms Research and Treatment Unit	<i>An illness that compromises or ends your ability to maintain even minimal normal daily activity inc. work/school without incapacitation &amp; deterioration on a chronic basis requires similar investment, research &amp; provision of a supportive/relevant treatment model of medical, practical welfare &amp; wellbeing care as given to someone diagnosed with other seriously life changing/life limiting illnesses such as MS, cancer (Macmillan) &amp; MND, etc. Anything less is effectively medically negligent.</i>
<b>796</b>	Surrey - South West London and Surrey Chronic Fatigue Service	<i>i think I facebook groups and my own research helped me more but was good to meet people in a similar position.</i>
<b>797</b>	Blackburn - North West Fatigue Clinic	<i>I very rarely go anywhere near a doctor as they have nothing to offer</i>