

## Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management

Consultation on draft guideline – deadline for comments 5pm on 22/12/20 email: [cfs@nice.org.uk](mailto:cfs@nice.org.uk)

	<p><b>Please read the checklist for submitting comments at the end of this form.</b> We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.</p> <p>In addition to your comments below on our guideline documents, we would like to hear your views on these questions:</p> <ol style="list-style-type: none"><li>1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.</li><li>2. Would implementation of any of the draft recommendations have significant cost implications?</li><li>3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)</li></ol> <p>See <a href="#">Developing NICE guidance: how to get involved</a> for suggestions of general points to think about when commenting.</p>
<p><b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>[Insert organisation name]</p> <p><b>INVEST in ME RESEARCH</b></p> <p><b>Charity Nr. 1153730</b></p>
<p><b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or</p>	<p>[Insert disclosure here]</p> <p>None</p>

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funding from, the tobacco industry.				
<b>Name of commentator person completing form:</b>		[Insert your name here] <b>Kathleen McCall</b>		
<b>Type</b>		[office use only]		
<b>Comment number</b>	<b>Document</b> [guideline, evidence review A, B, C etc., methods or other (please specify which)]	<b>Page number</b> Or <b>'general'</b> for comments on whole document	<b>Line number</b> Or <b>'general'</b> for comments on whole document	<b>Comments</b>  Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.
1	Guideline	1	5	<p>We commented on terminology used by NICE fourteen years ago when we commented on the draft guidelines and the finalised guidelines CG53.</p> <p>You should not be using Encephalopathy – use the term used by the WHO.</p> <p>The 2007 guidelines (CG53) used the term CFS/ME – so perhaps you need to explain why the old guidelines (the “Gold Standard” as described by NICE director Professor Littlejohn) referred CFS/ME but are now being updated by these draft guidelines to use ME/CFS.</p>
2	Guideline	General	General	<p>As we comment later in this document there must be a section at the beginning of the guidelines that describes the disease.</p> <p>You reference the IOM report – maybe you should use that description and add it to the Context section later in the Guidelines, and then move that section to the beginning.</p>

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3	Guideline	3	2	<p>An introduction to the disease is required in the Contents, before Recommendations.</p> <p>You need to describe ME here in order to set the scene for GPs and those others for whom this document is intended. (the 2007 guidelines had an introduction of sorts)</p> <p>The guideline needs to include an introduction that gives general information on ME/CFS such as numbers affected, the most common triggers etc.</p> <p>It should also describe the terms being used and the reason for the update – and possibly admit to the flaws in the 2007 guidelines that were rejected by (most) charities.</p> <p>The introduction should mention the WHO ICD-10 classification G93.3 and as well as ICD-11 classification code of 8E49.</p> <p>WHO ICD-10 and ICD-11 both use postviral fatigue syndrome as the lead term and include myalgic encephalomyelitis in ICD-10 with chronic fatigue syndrome in the alphabetical index/indexed to G93.3. ICD-11 includes both myalgic encephalomyelitis and chronic fatigue syndrome under the lead term post viral fatigue syndrome.</p> <p>WHO does not use the term myalgic encephalopathy – neither should you! Even if SNOMED (code 52702003) does accept that term it would make far more sense, and be more responsible of NICE, to use the term that WHO uses as the preferred term in order to reduce the amount of confusion and possibly mistakes.</p> <p>The correct coding and terminology is important for data collection on the incidence and prevalence and healthcare planning and you could aid in this aspect by standardising on the WHO terminology. It would help GPs, commissioners and other healthcare professionals see the category of disease they are dealing with. It should not be left open for speculation.</p> <p>Re-education of healthcare professionals should start here in the introduction.</p>

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				<p>Many of the specialist services that were set up following on from the 2007 guidelines were within mental health services headed by a spectrum of professionals with no one speciality adopting ME/CFS.</p> <p>These guidelines need to describe ME, CFS and the reason for the use of ME/CFS to avoid free for all interpretation happening again.</p>
4	Guideline	4	5	<p>As you base these guidelines on the IOM report then why do you not use the same definition for ME?</p> <p>Here it is –</p> <p>" ME/CFS is a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients."</p> <p>reference: Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine Washington (DC): National Academies Press (US); 2015 Feb 10. The National Academies Collection: Reports funded by National Institutes of Health. PMID: 25695122</p>
5	Guideline	4	16	<p>1.1.2 Recognise that people with ME/CFS may have experienced prejudice</p> <p>This should read</p> <p>1.1.2 Recognise that <b>many</b> people with ME/CFS have experienced prejudice</p>
6	Guideline	4	16	

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				<p>It might be helpful to mention here that the previous 2007 NICE guideline and its recommendations, and the travel of research and clinical considerations that followed, contributed to the prejudice, stigma and build-up of distrust between patients and healthcare professionals.</p> <p>Maybe it should be mentioned in the introduction rather than here (see our comment 3)?</p>
7	Guideline	4	17-18	<p>This should read "...who do not understand this disease". The inference in your terminology is that this is peculiar to the individual.</p> <p>If it affects 250,000 in the UK then it is more serious than other diseases such as MS or HIV/AIDS.</p>
8	Guideline	4	20	<p>should read</p> <p>".. they may have justifiably lost trust..."</p>
9	Guideline	5	15	<p>Should read "Explain and emphasise to people with ME/CFS ....."</p>
10	Guideline	5	20	<p>It might be useful to mention here that the 2007 guidelines and the travel of research that followed contributed to this prejudice and disbelief.</p> <p>There is a great deal of re-education that is needed to be arranged and performed in order to change the current thinking of healthcare professionals and social workers.</p>
11	Guideline	6	1	<p>The most important aspect is that health care and social care professionals truly need to listen to the child and believe in them and learn from them to be able to support them.</p>
12	Guideline	8	9	<p>There should be a recommendation for a minimum set of appropriate blood tests as well as most common "red flags"/other conditions to keep in mind for exclusion especially as it is known that there is a high rate of misdiagnosis?</p> <p>In the CG53 guidelines of 2007 NICE did include recommendations under chapter 1.2.2 History, examinations and investigations.</p>

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				<p>What has changed since 2007?</p> <p>You state in the evidence review – “The committee took the view that an exhaustive list of all possible conditions which might be considered was not possible, nor was it appropriate to provide advice on these conditions in this guideline, where there is relevant NICE guidance it is referenced in the recommendations.”</p> <p>There is no need for an exhaustive list but some of the most common examples of exclusions to keep in mind would be helpful as misdiagnosis is very common and GP appointments do not allow much time to be spent on each patient.</p>
13	Guideline	8	17	Should you mention here that these criteria are modified from the IOM 2015 criteria?
14	Guideline	9	17	<p>How would suspected ME/CFS be coded in healthcare records?</p> <p>Advice to GPs here would be useful.</p>
15	Guideline	10	17	To reduce their activities and listen to their bodies (common sense approach) would be the first item to mention
16	Guideline	11	7	<p>Who are these specialist teams experienced in ME?</p> <p>They do not exist now so where do they come from?</p> <p>What do they consist of?</p> <p>What training and experience do they require?</p> <p>Repeatedly trotting out this term “specialist team” means little when you do not have to define them or identify them.</p>
17	Guideline	11	8	Should this be care plan instead of management plan?
18	Guideline	11	8	<p>Is the diagnosis and care (management) plan taken care of by separate healthcare professionals?</p> <p>Who is in charge/takes responsibility for the overall care?</p>

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19	Guideline	11	10	<p>This is very precarious as there is no description of a specialist paediatric team.</p> <p>We know from experience how badly wrong this can go where a paediatric team is headed by somebody who does not believe in ME.</p> <p>This is where many lives begin to unravel. What are the definitions of specialist teams - who decides?</p>
20	Guideline	11	11	<p>Who is in charge of the child's overall care if there are various professionals involved?</p> <p>Why does the paediatrician who diagnoses the child need to refer further to a paediatric ME/CFS specialist team?</p> <p>As you probably know there are paediatric "<i>ME/CFS specialist teams</i>" that have considered ME as a problem arising from childhood trauma.</p> <p>How do you ensure that there are specialist paediatric teams available whose approach is in line with the new guidelines?</p>
21	Guideline	11	12	Should this be a care plan instead of management plan?
22	Guideline	11	13	The make-up of the desired specialist team should be described to give commissioners some direction as, at the moment, there is no national standard.
23	Guideline	11	16	NICE should recommend standard tools to be used for the assessment.
24	Guideline	12	10	Replace management plan with care plan
25	Guideline	12	27	Should that be worsening symptoms?
26	Guideline	13	2	Replace management plan with care plan
27	Guideline	13	10	Replace management plan with care plan

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28	Guideline	13	13	Replace management plan with care plan
29	Guideline	14	1	It would be best to learn from the child and provide the information they ask for. Find out what is important to the child.
30	Guideline	14	8	This is one of the most important aspects of this guideline. If you give all involved (patient, school, employers etc.) the right kind of information at the point of diagnosis then there is no need for all of the extra and unnecessary talk of tailored goal setting and other top down guidance.  Patients are just ill and have not lost their intelligence.
31	Guideline	14	10	What kind of sources would be considered reliable and up-to-date? Just collecting words without definition is irrelevant.
32	Guideline	14	19	Replace “often” with “can involve”
33	Guideline	14	20	Many patients remain at their baseline and experience no remission at all.
34	Guideline	14	21	Instead of flares and relapse use worsening of symptoms.
35	Guideline	15	4	who decides this information?  Giving information on some groups may lead to wrong or distorted information being given
36	Guideline	16	7	Who are these - what definition – where? Replace “should be” with “must be”. There are few who have training and experience in ME. How should they be trained and by whom?

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37	Guideline	16	14	It would be good to have information on where these trained and experienced professionals can be found. Is there a register of such professionals? Do they have training in ME in reality?
38	Guideline	18	15	It is not the fear that stops ME patients doing anything.  They know if they are well enough to leave the house or not.
39	Guideline	20	20	Replace management plan with care plan
40	Guideline	20	30	Replace management plan with care plan
41	Guideline	21	6	Replace “some” with “most” or “many”
42	Guideline	22	1	Replace management plan with care plan
43	Guideline	22	17	Is not the patient themselves the experts in self- management?
44	Guideline	22	19	Should this be managing worsening of symptoms? Flares and relapse imply that there has been a period of improved health?  For many ME/CFS patients the reality involves maintaining their level of health and avoiding making things worse.
45	Guideline	23	6	There are numerous mentions of specialist teams but there is no acknowledgement that there are very few teams in the UK that could be considered specialists. No mention of the training necessary, no mention of the cost of retraining, and in the current economic climate no chance of them being created.
46	Guideline	23	9	Replace management plan with care plan

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47	Guideline	23	10	Replace relapse with worsening of symptoms.
48	Guideline	24	1	Should it be caring for ME/CFS?
49	Guideline	24	4	Perhaps this should be stated in an introduction at the beginning (see our comment 3)
50	Guideline	24	6	<p>This section tries to please everyone and is open to anyone's interpretation. Advice on reducing activities and finding a level that is manageable should be considered as part of standard medical care.</p> <p>If patients feel supported and are allowed/encouraged to find their own limits/ judge their own function and monitored at regular follow-ups by their GP or a relevant specialist then that is all that is required.</p> <p>As there is no evidence for any treatment, management or therapy in ME/CFS then standard medical care principles should be followed.</p>
51	Guideline	24	18-24	<p>Lines 18 to 24 resemble dressed-downgraded exercise programme. It makes it sound as if patients cannot judge their limits themselves.</p> <p>They can if they are informed of the disease in an honest manner and told that one cannot exercise one's way out of ME/CFS.</p>
52	Guideline	25	1	This is a meaningless statement.
53	Guideline	25	5	<p>There is too much talk of plans and goals etc.</p> <p>It makes it all sound as if patients had lost the skill to live and need to be managed.</p>
54	Guideline	25	15	Again why specifically mention an activity plan as though it is an objective regardless of the disease. The objective is to get well not achieve a text-book goal.

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55	Guideline	25	19	<p>Why plan activity? Surely this must be done only of/when the patient can.</p> <p>By definition that means it cannot be planned.</p>
56	Guideline	26	4	again...continued emphasis on physical activity
57	Guideline	26	4	<p>Is it sensible to try to establish energy management plans for severe or very severe ME patients? One would think that provision of practical help and aids in managing the demands of daily living is required.</p> <p>You say in your rationale -                      “The committee agreed that if energy management strategies are inappropriately applied in people with severe or very severe ME/CFS this will increase the potential for harm. To reflect this, they recommended specialist advice and additional care in this group.”</p> <p>How confident is the guideline development group that there are enough specialists that can safely provide this advice?</p>
58	Guideline	26	16	This could be considered as part of standard medical care for anyone with a long-term chronic condition and is welcomed.
59	Guideline	27	20	<p>The committee justifies this physical activity chapter with their statement –</p> <p>“Because of the harms reported in the qualitative evidence, as well as the committee’s experience of the effects when people exceed the limits of their energy envelope, <b>the committee recommended that people with ME/CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in ME/CFS. The committee reinforced there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS.</b>”</p> <p>What is the purpose of this physical activity then if it is not a treatment or cure?</p>

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				<p>An evidence based guideline should stick to evidence and this chapter is very confusing as it tries to cover all bases and leaves it open to anyone’s interpretation.</p> <p>It tries to shoehorn exercise into the guideline whilst saying there is no evidence to support it and leaves the door open for out-dated and discredited models to continue.</p> <p>The previous chapters of energy management and physical maintenance should suffice.</p> <p>As and when patients feel their energy envelope limits increase they start to do more intuitively.</p> <p>It does not need to be made up into another “management” plan.</p> <p>We make the observation that this guideline seemingly tries to overturn the 2007 guideline by addressing the same therapies in a more “patient friendly” way instead of starting from a blank page and just going by the evidence.</p> <p>If there is no evidence of any treatment then we feel it would be best to follow standard medical care principles until more evidence is established.</p> <p>In 2017 liMER representatives met the deputy CMO of England and what was said then still applies we feel:</p> <p>“In Practical terms: we need physician led services (very few of which currently exist) which provide help and continued surveillance. ME is an identifiable problem due to the characteristic of post exertional malaise (PEM). Surveillance is needed as other diseases such as lymphoma can be hidden in that cohort.”</p> <p><a href="https://investinme.org/IIME-Newslet-1701-01.shtml">https://investinme.org/IIME-Newslet-1701-01.shtml</a></p>
60	Guideline	28	16	In 1.11.16 you instructed <b>not to offer</b> –

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				<ul style="list-style-type: none"> <li>any therapy based on physical activity or exercise as a treatment or cure for ME/CFS</li> <li>generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses</li> </ul> <p>Now in this 1.11.18 you state “</p> <ul style="list-style-type: none"> <li>A physical activity programme, if offered, should ....”</li> </ul> <p>Conflicting and dangerous statements. What a mess!</p> <p>In any case, most of the physiotherapists and OTs that have specialised in ME/CFS in the past 13 years need to be retrained.</p>
61	Guideline	28	19	The same thing could be said about almost anything including GET so why not just stay with the evidence and remove this whole chapter of physical activity.
62	Guideline	28	20	This sort of statement is meaningless. How does the physiotherapist or OT judge who benefits, is made worse or experiences no difference? It is only by trial and error.
63	Guideline	29	20-22	<p>In the NICE guidelines of 2007 advised against sleep in the day.</p> <p>In CG53 from 2007 it was stated –</p> <p>“1.4.2.3 Sleep management strategies should not include encouraging daytime sleeping and naps. People with CFS/ME should be advised that excessive sleep does not generally improve physical or mental functioning, and excessive periods of daytime sleep or frequent napping may further disrupt the sleep–wake cycle.”</p> <p>Now the 2020 draft guidelines state –</p>

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				<p>“</p> <ul style="list-style-type: none"> <li>how to introduce rest periods into their daily routine, including how often and for how long, as appropriate for each person”</li> </ul> <p>How strange that NICE took 13 years to agree with us that patient should do what they need to when they need to – despite there being no new research evidence.</p> <p>Only properly conducted sleep investigations can determine what is appropriate for each person.</p>
64	Guideline	32	8	<p>Are there enough dietitians who specialise in ME/CFS to fulfil this recommendation? What is NICE’s solution if not?</p>
65	Guideline	32	22	<p>Are there enough paediatric dietitians who specialise in ME/CFS to cover the demand?</p>
66	Guideline	33	44	<p>Are there enough dietitians who specialise in ME/CFS to fulfil this recommendation?</p>
67	Guideline	34	1	<p>In your evidence summary you state that there is no evidence for non-pharmacological or pharmacological therapies. You should stick to that evidence and not hang on to remnants of the past guideline.</p> <p>There is no need specifically to mention CBT here as your evidence review found CBT research into ME/CFS to be of low or very low quality.</p> <p>The Royal College of Psychiatrists say:</p> <p>“When does CBT help? CBT has been shown to help with many different types of problems. These include: anxiety, depression, panic, phobias (including agoraphobia and social phobia), stress, bulimia, obsessive-compulsive disorder, post-traumatic stress disorder, bipolar disorder and psychosis. CBT may also help if you have difficulties with anger, a low opinion of yourself or physical health problems, like pain or fatigue.”</p>

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				<p>Based on the above description this topic is already covered in the section “Managing coexisting conditions” on page 36 lines 12 to 20 with links to relevant NICE guidelines.</p> <p>“For recommendations on identifying and treating associated or comorbid 13 anxiety, depression or mood disorders see the: 14 • NICE guideline on depression in adults 15 • NICE guideline on depression in adults with a chronic physical health 16 problem 17 • NICE guideline on depression in children and young people 18 • NICE guideline on generalised anxiety disorder and panic disorder in 19 adults 20 • NICE guideline on common mental health problems.”</p> <p>Coping with symptoms of ME/CFS is covered by earlier sections of energy management. “1.11.2 Discuss with people with ME/CFS the principles of energy management, its role in supporting them to live with their symptoms, the potential benefits and risks and what they should expect.”</p>
68	Guideline	34	6-8	<p>Instead of general psychological therapies it appears that you have chosen to highlight CBT only simply because the current specialist services offer it. That is not a good reason to justify this or to continue to promote this therapy especially as you already admit that the evidence base is poor.</p> <p>Referencing your own words – “CBT is currently provided for people with ME/CFS in specialist services. These recommendations clarify when CBT should be offered to people with ME/CFS”.</p>
69	Guideline	34	16-20	<p>All of the history behind CBT and the funding awards for research using CBT and the practices of vested interests pushing this have been predicated on assuming ME patients have abnormal illness beliefs. This is blatant falsehood from NICE and we are surprised that members of the committee have agreed to leave this in guidelines.</p> <p>It is unfit and a waste of NHS resources</p>

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				This applies to the whole section which should be removed.
70	Guideline	34	30	<p>The lines 1 to 13 do not offer any assurance that the CBT described here is any different from the current practice. It talks about meaningful goals, priorities, sleep, activity and rest.</p> <p>This whole section gives too much credence to a talking therapy that you have found to have a low or very low evidence base for ME/CFS.</p>
71	Guideline	35	15-17	<p>There is no evidence of efficacy of CBT for children with ME/CFS. Why even mention it here?</p> <p>If children feel supported and listened to all the way through the investigations/diagnosis/follow- up then there is less likely to occur any problems that need psychological intervention.</p> <p>Any such interventions should be addressed separately by professionals trained to deal with such problems and not by healthcare professionals who have had a weekend course in CBT or not plugged by a compromised national institute that ought to be concerned with clinical excellence.</p>
72	Guideline	35	25	<p>Severe or very severely ill patients surely do not have excess capacity to engage in any therapy needing cognition.</p> <p>All their energies are taken by basic needs</p> <p>Remove this.</p>
73	Guideline	37	1	<p>Should the title be Managing worsening of symptoms?</p> <p>Many patients adapt to living within their limits and flares or relapse imply that patients are normally ok but flares and relapse happen at times and can be managed by following some agreed plan.</p>



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				<p>There is too much talk of a plan. It should be very simple such as increase activity when possible, decrease when necessary.</p> <p>The patient must be in charge. Knowledgeable healthcare professionals can be sought for advice if necessary.</p>
74	Guideline	37	9	Remove word “temporarily”.
75	Guideline	37	18	The most important aspect here should be assessing the patient and not reviewing a management plan.
76	Guideline	37	23	If the patient’s condition worsens for years then the most important thing is to monitor the patient.
77	Guideline	38	3	<p>Things should not be more complicated than necessary.</p> <p>Simply, Increase activity when possible, decrease when necessary.</p> <p>The patient must be in charge with knowledgeable healthcare professionals giving input if necessary/available/needed.</p>
78	Guideline	38	18	<p>What strategies might there be that can overturn decisions by insurance companies and corporate parasites employed by the DWP to oversee benefits assessments that coerce patients into following NICE guidelines - as has previously been the case for thirteen years since the last flawed NICE guidelines were published.</p> <p>There should be no nuances in NICE guidelines that only NICE Directors are aware.</p>
79	Guideline	38	21	First link did not work
80	Evidence review G	347	15-16	<p>Evidence review G re Flares and Relapse on page 347 lines 15 and 16</p> <p>“The committee noted this was a common part of ME/CFS and had explained in the Information and support section of the guideline that ME/CFS involves periods of remission and relapse.”</p>

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				Remission implies that patients are well at times. Many ME/CFS patients never experience remission but adapt to living at a certain level and others have a steady decline no matter what they do.
81	Guideline	39	1	<p>This is far more important than any management plan.</p> <p>A regular review of the patient, just like in any other chronic illness, should be part of ME/CFS patient's care.</p> <p>Many other illnesses can hide in this patient group. Misdiagnosis is common.</p>
82	Guideline	39	14	<p>Is this not the wrong emphasis and terminology?</p> <p>Patients with ME are ill - they are not in some contest where achievement is the aim. This is about health.</p>
83	Guideline	39	16	Why does self management have to concentrate on activity?
84	Guideline	40	17	<p>Most of the current specialist services need to be educated themselves first before they can be trusted to educate others.</p> <p>Invest in ME Research and many of our supporters have consistently campaigned for CBT and GET to be removed from the NICE guidelines since they first were introduced in 2007.</p> <p>For thirteen years, Invest in ME Research has provided education to counter the official misinformation. Our cpd-accredited international ME conferences has provided education from a round the world - how much has been used by "specialist services" that you assume exist?</p>
85	Guideline	41	4	First link did not work
86	Guideline	43	8	Why is CBT mentioned here specifically rather than a general term?

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				<p>Instead refer to psychological therapies if you need to.</p> <p>Again shows the bias by NICE to retain CBT despite lack of evidence of efficacy.</p>
87	Guideline	44	18	<p>Is it necessary to introduce yet another term (PESE) when the term PEM is well established in the literature and used in research criteria? Of course, there is no need.</p> <p>There should be some basis in the literature for changes like this to be used in NICE guidelines. Otherwise, we will end up using various terms as and when people choose to do so.</p> <p>Terminology within ME is already a mess – NICE are just further complicating the picture. Is this done on purpose?</p>
88	Guideline	44	21	<p>Remove the word “also” as post exertional malaise (PEM) is the most commonly used term.</p> <p>It may not exactly describe what patients experience but NICE consensus guidelines cannot just decide to use yet another term.</p> <p>This is so negligent of NICE.</p> <p>Evidence review Diagnosis page 44 Table 4 -</p> <p>“Post-exertional symptom exacerbation (PESE) Note: the committee’s preferred term is PESE”</p>
89	Guideline	45	21	<p>All of the recommendations seem too general and without any proper explanation or thought behind them that it is impossible to make any comment on them.</p> <p>If the recommendations were meant to be based on the content of the NICE guidelines then collecting information on patients using standardised and validated tools would be a good starting point.</p>
90	Guideline	47	2	<p>Rather study the underlying sleep issues with ME in a proper sleep clinic fashion</p>

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91	Guideline	47	13-14	<p>What caused this?</p> <p>Surely it was partly due to poor NICE guidance in the past.</p> <p>Perhaps that should be recognised.</p> <p>In any case this needs to be stated in an introduction at the beginning of the guidelines (see our comment 3 above).</p>
92	Guideline	48	1-6	<p>This does not just apply to ME - it would be the same for all diseases where a patient has had a bad experience.</p> <p>The real issue is that these bad experiences are based on the fact that healthcare professionals have been fed misinformation and false beliefs - which has then in turn affected their perception and treatment of ME patients.</p> <p>Again, NICE ducking the real issue.</p>
93	Guideline	48	23-24	<p>The document talks about specialist services and multidisciplinary teams throughout the document. There are very few specialists or multidisciplinary teams in the UK.</p> <p>It is quite obvious to us that there needs to be more resources for providing the care outlined in this document. Of course additional resources are required to overcome discriminatory practices which have been built up from erroneous guidelines in the past.</p> <p>Early diagnosis is going to demand more resources especially as the current ME/CFS services tend only to operate part-time.</p> <p>Proper diagnostic criteria are required to be standardised.</p> <p>This document will not in itself change much for patients</p>

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94	Guideline	52	26	Current practice recommends a set of basic blood tests and lists some “red flags”. Would it be prudent to retain these basic blood test from the current guideline?
95	Guideline	53	3	What course of action or treatment would you think could be offered at an earlier stage to prevent disease progression when not enough research has been funded to identify what might prevent such progression.  <b>But thank you for finally admitting that ME is a disease.</b>
96	Guideline	53	5	It would be good to define the specialist team. What is the minimum staffing requirement for such a team?
97	Guideline	54	10-12	It is therefore important not to offer any form of therapy that has no evidence base.  It is better to use the principles of standard medical care, offer common sense advice, and explain the current state of knowledge in an honest and straightforward manner.
98	Guideline	55	3	NICE should organise a publicity campaign to expel the myths that have permeated all levels of public policy about ME/CFS.
99	Guideline	56	8 – 9	We doubt this very much.  Of course it will require more resources as existing social services staff need to be re-educated and there is little knowledge of ME at present.
100	Guideline	56	26 – 29	There needs to be some practical solution offered here. We need to establish places around UK that have experience and knowledge about severe or very severe ME/CFS and can provide advice as necessary.
101	Guideline	58	3-4	It is not just “leaving school” - but being excluded from school.

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				This should be specifically stated - often children are excluded because of the illness with schools making little effort to assist in adjusting to the child's needs – both short and long term.
102	Guideline	58	16	This is doubtful.  It will require adjustment from school teachers and possibly classes – possibly re-training.
103	Guideline	59	21-24	This almost inevitably will lead to addition of new staff in the current climate where resources are already limited - if the intent is really to improve the care of people with ME. It will require re-training.
104	Guideline	60	2	You state there was limited evidence for any intervention to manage ME/CFS and this was supported by the committee's experience yet you go on to assess some interventions in detail.  This does not make sense. In practice, you can only recommend standard medical care.
105	Guideline	60	25	Not confusion - NICE were told that GET should not be recommended for people with ME when the 2007 guidelines recommended it. NICE did not listen. Stop obfuscating the lack of responsibility shown by NICE in flawed recommendations. There has been no confusion from patients.
106	Guideline	61	13	What specific circumstances?  Please define.
107	Guideline	62	2	It is worth noting that there is no clinical trial evidence to justify recommendation of energy management.  There is only patient experience and patients do this because it is common sense and guided by their instinct rather than some proven intervention.

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108	Guideline	63	7	<p>Interesting that nothing has changed since 2007 in terms of research and now you admit what patients have been saying since 2007.</p> <p>What a waste of 13 years where the lives of people with ME have been compromised by poor NICE guidelines.</p> <p>Maybe you need to include an apology.</p>
109	Guideline	67	23-29	<p>CBT should not be offered in this guideline</p> <p>The Royal College of Psychiatrists say:</p> <p>“When does CBT help? CBT has been shown to help with many different types of problems. These include: anxiety, depression, panic, phobias (including agoraphobia and social phobia), stress, bulimia, obsessive-compulsive disorder, post-traumatic stress disorder, bipolar disorder and psychosis. CBT may also help if you have difficulties with anger, a low opinion of yourself or physical health problems, like pain or fatigue.”</p> <p>Based on the above description this topic is already covered in the section “Managing coexisting conditions” on page 36 lines 12 to 20 with links to relevant NICE guidelines.</p> <p>There is no good evidence of efficacy of CBT and it needs to be removed.</p>
110	Guideline	71	9	<p>We feel that this section needs to be expanded upon and should be relocated to the beginning of this document in order to set the scene before reading whatever final guidelines are produced.</p>
111	Guideline	71	11-12	<p>It is not in NICE's remit to discuss or amend the name myalgic encephalomyelitis. You should remove this. Names of diseases are not always accurate and there is no value in cherry-picking symptoms to discuss/debate at this point. Chronic Fatigue Syndrome is not necessarily accurate either.</p>

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				<p>Research will eventually decide the name once credible evidence is found to satisfy everything. Until then NICE should not dabble in name changing.</p> <p>WHO recognises myalgic encephalomyelitis. It does not recognise encephalopathy. Use the WHO classification.</p>
112	Guideline	72	12	<p>You may mention that patients challenged the NICE guidelines of 2007 and took NICE to a judicial review..</p>
113	Guideline	72	19	<p>What are these major studies?</p> <p>This is important in order to determine what triggers a review of guidelines.</p> <p>Previously NICE have been tardy in complying with patients' wishes to review the flawed 2007 guidelines.</p>
114	Guideline	General	General	<p>You asked –</p> <p>In addition to your comments below on our guideline documents, we would like to hear your views on these questions:</p> <ol style="list-style-type: none"> <li>1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.</li> </ol> <ul style="list-style-type: none"> <li>• Providing timely and correct diagnosis             <ul style="list-style-type: none"> <li>o Challenging for both patients and doctors as not enough doctors who understand ME/CFS</li> <li>o The document mentions the word “specialist” numerous times but does not define the specialist or where/how patients are going to be able to access them. There needs to be funding for specialists. This will be extremely challenging in the current environment and</li> </ul> </li> </ul>

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				<p>history dictates that ME will likely not receive the amount of funding for these specialists that is required.</p> <ul style="list-style-type: none"> <li>o Challenging for medical education as there is considerable effort needed to get rid of the thinking that ME/CFS is caused by childhood trauma, for example.</li> </ul> <ul style="list-style-type: none"> <li>• Providing ongoing care <ul style="list-style-type: none"> <li>o Challenging to undo the harm that long-term patients have suffered as a consequence of the 2007 CG53 guideline recommendations and the apathetic approach to ME that governments, the NHS, MRC and NICE have taken toward ME.</li> <li>o Challenging to encourage commissioners to fund specialist care that satisfies the demand</li> <li>o Challenging to healthcare providers to get long-term patients to trust them and reconnect with healthcare as many have not seen a doctor for their ME/CFS for years.</li> <li>o Challenging to NHS to re-educate ME/CFS service providers that followed the information in the 2007 guidelines and the research that the public funders supported. Getting them to acknowledge that their care set ups need to be overhauled.</li> </ul> </li> <li>• Providing appropriate care and follow up for the very severely affected patients that have special needs. <ul style="list-style-type: none"> <li>o Hospitals for example cannot guarantee isolation from noise, light, smells etc. How to accommodate for all the special requests and requirements in practice?</li> <li>o There are not enough knowledgeable healthcare staff to advice on problems with tube feeding and other dietary issues for example. Not enough dieticians in general and even less so those that understand ME/CFS.</li> <li>o Not enough healthcare professionals who do home visits</li> </ul> </li> <li>• Treating children with ME/CFS with respect and listening to them <ul style="list-style-type: none"> <li>o Challenging for social services and paediatricians to understand that ME/CFS is a disease that does not require child protection orders to be implemented just because the child has been diagnosed with ME/CFS</li> </ul> </li> </ul>
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				<p>2. Would implementation of any of the draft recommendations have significant cost implications?</p> <ul style="list-style-type: none"> <li>• Medical education on ME/CFS needs to be standardised and updated as required. Needs funding.</li> <li>• GPs need to follow up their ME/CFS patients just as they do any other of their chronically ill patients so that they can provide medical evidence for DWP assessments for example.</li> <li>• ME/CFS services need to connect to research initiatives to foster learning and collaboration. This needs funding.</li> <li>• Very severely ill ME/CFS patients need in-patient facilities and respite care offered to carers that are often family members. Funding is required for this.</li> </ul> <p>3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)</p> <ul style="list-style-type: none"> <li>• There needs to be major investment in all areas of ME/CFS biomedical research to help provide good evidence for policies that guide patient care.</li> <li>• Invest in ME Research has been involved in funding and initiating ME/CFS research at Quadram Institute in Norwich since 2013. The charity initiated partnership involves the local East Coast Community Health ME/CFS clinic and is an example of good collaborative practice that has been initiated by patients and carers without any support from public funding.</li> </ul>
115	Guideline	General	General	<p>It would be prudent to produce separate sections of the guidelines for children and for severely affected (maybe even splitting this category into severe and very severe sections). At the moment these groups get lost in the overall text.</p> <p>The specific information concerning children and severe, very severe ME patients should be clearly visible and not imbedded in the overall text.</p> <p>This will aid healthcare staff in understanding and treating the disease better.</p>

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				The draft guidelines are a cumbersome document to read and need more clarity.
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Insert extra rows as needed

### Checklist for submitting comments

- Use this comment form and submit it as a **Word document (not a PDF)**.
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include **page and line number (not section number)** of the text each comment is about.
- Combine all comments from your organisation into 1 response. **We cannot accept more than 1 response from each organisation.**
- Do not paste other tables into this table – type directly into the table.
- Ensure each comment stands alone; do not cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- Spell out any abbreviations you use
- For copyright reasons, **do not include attachments** such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.
- **We have not reviewed the evidence for the recommendations shaded in grey. Therefore, please do not submit comments relating to these recommendations as we cannot accept comments on them.**
- **We do not accept comments submitted after the deadline stated for close of consultation.**

You can see any guidance that we have produced on topics related to this guideline by checking [NICE Pathways](#).

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