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

	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. 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. In addition to your comments below on our guideline documents, we would like to hear your views on these questions: 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) See Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	Science for ME (S4ME)

Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	None
Name of commentator person completing form:	
Type	[office use only]

Comment number	**Document** **[guideline, evidence review A, B, C etc., methods or other (please specify which)]**	**Page number** Or **'general'** for comments on whole document	**Line number** Or **'general'** for comments on whole document	**Comments** 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	General	General	**Introduction to our submission** Our submission is based on extensive discussions of the guideline by members of a science-focused ME/CFS online forum (Science for ME), which has a diverse membership that includes people with ME/CFS of all severity levels, carers, scientists and clinicians. We thank the ME/CFS guideline committee and NICE staff for their good work on this guideline to date. The outcome, as evidenced by the draft, is a significant step towards improving services for people with ME/CFS and correcting stigmatising views and approaches. We commend the committee for the thoroughness and scientifically sound approach of their examination of the research into therapies intended to treat or cure ME/CFS. We ask the committee to be equally rigorous in their use of evidence for other aspects of their recommendations.

				Having given careful consideration to the guideline recommendations and supplementary documentation, we provide detailed recommended changes which would better reflect the outcomes of the evidence reviews, while removing some of the assumptions and decisions based solely on the committee members' experience. We highlight here three main areas of concern: 1. Diagnosis: We agree that the IOM (Institute of Medicine) criteria form a suitable basis for clinical diagnosis. However, the committee has made significant changes to the IOM criteria which will exclude a number of people from being diagnosed with ME/CFS, despite meeting the requirements of the IOM criteria. We do not think the experience of a small committee is an adequate basis for creating new untested criteria with the result that people who do not exhibit cognitive difficulties may be denied appropriate diagnosis and condition management, potentially leading to harm. 2 Management: People with ME/CFS need input from medical and care services to help them learn how they can manage their limited energy in order to reduce the occurrence of post-exertional malaise (PEM) and long term deterioration. We have recommended a more straightforward self management approach using symptom-contingent pacing, with guidance as needed from specialist nurses who can also help with managing symptoms, including reviewing medications, with making necessary life changes, and by providing informal wellbeing support for those who want to talk about feelings that arise naturally as a result of living with a chronic debilitating illness. Physical activity programmes for those whose symptoms have improved, and CBT for psychological support, are neither evidence based, nor necessary. We recommend they be removed from the guideline, where their inclusion presents a real risk of harm, with GET and directive CBT continuing to be provided under different names. 3 Terms used in the guideline: We are concerned that some of the terms introduced or defined are an unnecessary departure from current usage by clinicians, researchers, people with ME/CFS and in publications. This will add a further layer of misunderstanding and hamper communication between people with ME/CFS and their clinicians. Of particular concern are the introduction of the colloquial and easily misinterpreted 'energy envelope' and 'flare'; the complete lack of mention of 'pacing'; and the renaming of the almost universally recognised term 'post-exertional malaise', which has been replaced with the vague and misleading 'post-exertional symptom exacerbation'. The recommendations that address the requirements of people with severe and very severe ME/CFS will make a real difference to wellbeing for many with ME/CFS. We have noted that people with less severe illness may also

				require similar accommodations, especially during periods of deterioration. Finally, we note that the improvements to the guideline are a necessary, important step, but it will take commitment and cooperation from many to achieve the complete re-orientation of ME/CFS services that is required. We urge the committee to build into the guideline safeguards and requirements for accountability to ensure that the promise of evidence-based patient care is realised.
2	Guideline	General	General	**Medical care models and the use of evidence.** NICE guidance for the management of conditions for which there is no effective treatment must be based on the best available evidence, just as it is for conditions for which there are effective treatments. Where the guideline cannot make evidence-based recommendations that may lead to improvements, it must fulfil its brief to ensure recommendations do not lead to deterioration or harms. We ask the committee, in reviewing stakeholder feedback and amending the guideline, to examine the approach they have used in developing their recommended model of care, the assumptions underlying the recommendations, and whether the included recommendations are well supported by their own evidence reviews. The committee has made recommendations that can be implemented by minor adaptations to current service provision utilising the therapist specialisms that are currently providing CBT and GET as treatments for ME/CFS. This may have the short-term advantage of causing minimal upheaval to services, upset to healthcare professionals with entrenched beliefs about cause of or appropriate treatment for ME/CFS, and prima facie appear to be cost-efficient. It may also seem that switching from providing programmes on GET or CBT to courses on 'energy management' is a good fit, with CBT therapists providing psychological support as they do so. However, the clinical effectiveness evidence for CBT for ME/CFS was all of low or very low quality (Evidence Review G, pp.72-119, p. 318 line 23). There can therefore be no justification for provision of ME/CFS services by CBT therapists, as to provide support for other aspects of care, such as energy management or medical symptoms, would exceed the bounds of their expertise and risk harm to people with ME/CFS. Services staffed by healthcare professionals (HCP) who have provided GET and CBT as treatment for ME/CFS for years are likely to continue to foster a shared mindset amongst staff that ME/CFS can be treated by increasing physical activity or changing thoughts and behaviours. Retraining of such staff is unlikely to be adequate to prevent old methods from creeping into updated approaches, and harms to people with ME/CFS from resulting. It should also be self-evident that provision of CBT for ME/CFS is not cost-effective because there is no good quality effectiveness evidence to support it.

				In the review of qualitative evidence, themes of validation, relationship with therapist and support were found not to be specific to CBT (Evidence Review G, p.324 lines 41-43). Support, validating patient experience, listening and building rapport are elements of care that may be provided in interactions with any healthcare professional (HCP). Our members report that the natural reactions to living with a chronic debilitating disease, such as frustration and sadness, are often helped more by assistance with the practicalities of the major upheaval to their lives, and from ready access to an HCP who understands all aspects of their condition, than from undergoing a psychological therapy, which itself depletes already scarce energy and may lead to worsening. There is likewise no reliable evidence to support the recommendations for physical activity programmes for some people with ME/CFS, or to suggest that increasing by flexible increments while remaining within a person's 'energy envelope' is feasible as a concept, has benefits (as suggested at 1.11.19) or is safe. The recommendations in the subsection on 'Physical activity' present a form of graded exercise therapy, for which the evidence review established, there is no reliable evidence. The portrayal in the guideline of activity programmes involving fixed increments as being poorly evidence and potentially harmful, and programmes involving flexible increments as acceptable and potentially beneficial is a false distinction, since it is clear that clinical studies of GET included in the effectiveness review **did** include non-fixed increments. There is no reliable evidence that people with ME/CFS who find their energy levels have improved would benefit from input from HCPs, with the possible exception of those transitioning from being bedbound to greater levels of mobility, for whom the recommendations under physical maintenance may be helpful alongside general advice and supervision from a physiotherapist with up-to-date ME/CFS training consistent with this guideline. Our members generally report being able to increase activity levels naturally without need of HCP input when they have experienced improvements in health. Such a 'hands-off' approach has the benefit of entailing no cost to the health system. The third area of management covered by the draft guideline is symptom management. In contrast to the level of detail and specification of models for energy management and the new versions of CBT recommended, there is very little in the way of detail on symptom management. Yet, for many people with ME/CFS, the main reasons for seeking assistance from health and care services relate to new or worsening medical symptoms of ME/CFS, which may be severe or very severe, including orthostatic intolerance, pain and gastrointestinal symptoms, and seeking help with the practicalities of making major life changes and arranging care needs. To adequately assist with such issues without exceeding competence or bounds of expertise, the HCP must hold appropriate qualifications in a suitable discipline and have relevant experience, and up-to-date training consistent with this guideline. Currently, there is no guidance as to what types of HCP will fulfil such roles.

				We therefore conclude that the model of care set out in the guideline, which will inevitably entail updating existing providers and continuing with provision of therapist-based services is neither evidence based, nor fit for purpose, and carries significant risk of continuing to cause harms of the type the guideline purports to set out to avoid. Instead we recommend a consultant-led model of care, with comprehensive support and care provided by specialist nurses. This would more closely mirror the fields and levels of expertise set out in the multiple sclerosis NICE Guideline (CG186), in which a consultant neurologist and specialist Multiple Sclerosis (MS) nurses are specified as relevant professionals to involve in the person with MS's care. Such a model would involve a specialist team led by a consultant from a relevant biomedical discipline with specialist knowledge of ME/CFS who would see new patients for thorough investigation and confirmation of diagnosis, with a team of specialist nurses providing the role of the HCP who will be the main contact for people with ME/CFS, and able to assist them with energy management, symptom management and informal psychological support. Provision of therapies such as physiotherapy, occupational therapy, and psychological support such as counselling, would be supplementary for those who want and need them. The advantages of this model: a) The nurse's skills and training enable them to help with advising and monitoring many aspects of the person's health needs, to deal with more than one issue during an interaction with the person with ME/CFS, and to liaise as needed with the consultant. This more comprehensive service is cost-effective, and is energy-efficient for the patient; b) Avoids harm, including by not facilitating the continuation of the unevidenced treatments of physical activity programmes and CBT, or the stigmatising ideas that underpin them; c) General practitioners are supported with access to specialist medical advice, while time-consuming patient education and support functions are carried out by nurses with specialist expertise; d) People with severe or very severe ME/CFS and their families and carers would receive specialist support. This provision of a medical care model, where the nurse helps patients of all severity levels, is vital for people with ME/CFS, as any individual's severity level can worsen rapidly, with the need for provision to be already in place for accessible specialist ME/CFS care. Finally, we set out the aims for medical care and support provision that we consider should guide the inclusion of

				any recommendation in this guideline: 1. Evidence based: That all treatment offered, whether intended to be curative, to improve symptoms or to prevent worsening, be based on high quality scientific evidence. 2. First do no harm: That all medical and therapeutic care provided does no harm, whether by allowing harmful treatments to continue under new names, or by lack of provision of appropriate services that meet the needs of people with ME/CFS. 3. Accessible: That for people with ME/CFS of all severity levels, the provision of care can be accessed when needed in a form the patient can cope with without detriment to their health, and that takes account of their specific needs and limitations 4. Expert: That the person providing the advice, treatment or care has appropriate qualifications and experience, as well as up-to-date knowledge of ME/CFS in accordance with this guideline. 5. Efficient - in terms of cost, time and energy of the patient: With the same person understanding and able to advise on all their health needs, not having to see different people for energy and symptom advice and support with coping with life changes etc. 6. Consistent: medical support and care is provided by a single HCP who knows the person with ME/CFS and their needs, and can either help or refer on if needed.
3	Guideline	General	General	We have made comprehensive and detailed suggestions for changes to the draft guideline and we are only one of many stakeholders making a submission. The total amount of feedback for the Guideline Committee to consider will be large, with some points likely to provoke strongly opposing views. We therefore encourage the Committee to ensure that they have sufficient time to consider the stakeholder feedback and if necessary take longer than planned in doing so. We are sure that people with ME/CFS will understand some delay in order to produce the best possible guideline.
4	Guideline	General	General	**Medically Unexplained Symptoms (MUS)** When ME/CFS is mischaracterised as ‘medically unexplained symptoms’ (MUS), 'ME/CFS' may be viewed as a term for a cluster of non-specific symptoms overlapping with other poorly understood conditions (e.g. IBS) and undiagnosed symptoms, rather than as a term for the distinct medical condition, ME/CFS, as NICE acknowledges it to be.

				Approaches used for MUS (also referred to as 'persistent physical symptoms' (PPS)) are likely to be completely inappropriate for people with ME/CFS and may include physical activity programmes and CBT as treatment for MUS. This guideline recognises that these approaches should not be offered as treatments for ME/CFS and are potentially harmful. Services and clinicians taking this approach are unlikely to take the limitations imposed by post-exertional malaise and the absence of reliable effectiveness evidence for the application of MUS treatment approaches to ME/CFS adequately into consideration. Any characterising of ME/CFS as MUS therefore creates significant risk of harm to people with ME/CFS, both to their health and by causing a loss of trust in the health system, with no mitigating benefit. Therefore, in order to protect people with ME/CFS from harm, we ask that the guideline makes it clear that people with ME/CFS should not be referred to MUS services, and ME/CFS should not be framed as MUS (or PPS or similar terms) for diagnosis, assessment, management, treatment or any other purpose.
5	Guideline	4	5	The word 'complex' should be deleted. The underlying pathology is unknown so cannot validly be described as 'complex'. 'Complex' can be misunderstood to imply inaccurately that there are complex 'biopsychosocial' factors. It can also subtly imply that patients are 'difficult'.
6	Guideline	4	5-6	The first bullet point of 1.1.1 should include that onset of ME/CFS is typically triggered by an infectious illness.
7	Guideline	4	7	The words 'can have' should be replaced with 'has'. i.e., '*[ME/CFS] has a significant impact on people's (and their families and carers') quality of life*'. ME/CFS has a significant impact on the lives of all people with ME/CFS, regardless of severity level.
8	Guideline	4	10	The words '*affects each person differently*' should be deleted. This is true for all medical conditions. Highlighting it here suggests more variability than is the case and may lead to misdiagnoses. Diagnosis requires meeting specific criteria (section 1.2).
9	Guideline	4	10-11	The term 'substantial incapacity' is vague and the clause does not adequately convey the impact of severe and very severe ME/CFS or acknowledge the impact of ME/CFS for mild cases. Suggested wording: '*varies widely in severity - from mild ME/CFS where there is significant debility and greatly reduced capacity for activity to severe and very severe ME/CFS, where the person is bed-bound and requires comprehensive personal care*.'
10	Guideline	4	13	The words 'change unpredictably' should be qualified with 'sometimes', i.e. 'symptoms can sometimes change unpredictably'. There is often considerable predictability of nature and severity of the symptoms of ME/CFS. This predictability is the foundation of symptom-contingent pacing with the aim of avoiding post-exertional malaise (PEM).

11	Guideline	4	14-15	The words, '*ranging from being able to carry out most daily activities to severe debilitation*' should be deleted. It incorrectly gives the impression a given person with ME/CFS may range between being able to carry out most daily activities to severe debilitation over 'days, weeks or longer', implying severe and very severe ME/CFS may remit significantly over short time frames.
12	Guideline	4	15	We suggest addition of a fifth bullet point to 1.1.1, stating that there is no evidence that ME/CFS is a psychosomatic condition or caused or perpetuated by emotional distress or personality traits
13	Guideline	4	16-18	This clause should also recognise that ill-informed attitudes to ME/CFS have led to real harm for many people with ME/CFS. Suggested wording: '*Recognise that people with ME/CFS may have experienced prejudice, disbelief, felt stigmatised and been harmed by people who do not understand their illness*.' Thank you for acknowledging the prejudice that people with ME/CFS experience and pointing out its impact on perceptions of and willingness to engage with health services.
14	Guideline	5	3-4	What is meant by, '*acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them'*? The meaning of this clause is not clear. We suggest that for clarity, this bullet point be broken down into two bullet points: Suggested edit: 1. '*Provide the person with ME/CFS with information about the condition, including information on how it is likely to affect their daily life. See section 1.6 Information and support*.' 2. '*Listen to and acknowledge the person with ME/CFS' account of their experience of living with ME/CFS and its symptoms and how these affect them. Do not seek to minimise the impact of the illness*.'
15	Guideline	5	5	We are pleased to see inclusion of recommendations on building supportive, trusting and empathetic relationships.
16	Guideline	5	8	We suggest inclusion of a fifth bullet point in 1.1.3, as follows: *'ensure that the person with ME/CFS is fully informed about and involved in all aspects of the planning and delivery of their care.'*
17	Guideline	5	9-14	We are pleased to see recognition that people with ME/CFS need early and accurate diagnosis, and regular monitoring and review.
18	Guideline	5	15-18	Include that refusal of assessment for and development of the 'management plan' or refusal to restart any part of it should be acceptable without this affecting other aspects of care. Suggested wording: '*Explain to people with ME/CFS and their family or carers (if appropriate) that they have the right to decline assessment for and development of the* management plan (medical care plan), *or to decline, withdraw from or refuse to restart any part of their management plan and it will not affect other aspects of their care*.'
19	Guideline	5	16	We consider the term 'medical care plan' to be more appropriate than 'management plan'. The former makes it clear that it is a plan to deliver care. The term 'management plan' implies that the person with ME/CFS and their

				condition are to be managed. All uses of ‘management plan’ throughout the draft guideline should be changed to ‘medical care plan’.
20	Guideline	5	18	There are no treatments for ME/CFS, so what treatments or otherwise are being referred to in using the term ‘intervention’? The term ‘intervention’ should not be used. It has connotations of people being told 'hard truths' about their behaviour in order to bring about improvement. As there is no treatment for ME/CFS, the types of medical assistance that can be provided may be better termed 'support' than 'intervention'.
21	Guideline	6	7-27	We think this section represents a significant advance in clearly stating the needs of people with severe and very severe ME/CFS and how these can be met. We include a reaction of an S4ME forum member with ME/CFS to illustrate this: '*it made me cry with happiness when I read it - and the sense of sheer relief in this house when we read it. I just ask that it does not get diluted down, please, because this section will help me not only with hospital care, but social services, with my MP, with housing, even just other people personally...with every aspect of my life.'*
22	Guideline	6	7-29	We suggest renaming the subheading 'Awareness of severe or very severe ME/CFS and its impact' to 'Symptoms of ME/CFS and their impact'. Replace 'Be aware that people with severe or very severe ME/CFS' (line 8) with 'Be aware that people with ME/CFS'. While people with severe and very severe ME/CFS may experience these symptoms all of the time, people with less severe illness may also experience these symptoms, particularly during PEM. Remove ‘and constant’ from the clause ‘severe and constant pain’ (line 12) Remove the words 'severe or very severe' from line 28 (1.1.9). Add a subheading, 'People with severe or very severe ME/CFS' at page 7 line 17 before 1.1.10. 1.1.8 and 1.1.9 would then address all people with ME/CFS of all severity levels, and take into account that while people with severe or very severe ME/CFS may experience symptoms in 1.1.8 and require recognition of the impact of symptoms as detailed in 1.1.9 all the time, symptoms and debility for people with mild or moderate ME/CFS may match those of severe or very severe ME/CFS during PEM or prolonged deterioration. The guideline should not give the impression (as it does currently) that mild and moderate ME/CFS does not involve these symptoms impacting wellbeing, communication, mobility and ability to interact with others and care for themselves. Accommodations need to be made to help people with ME/CFS of all severity levels avoid over-exerting and triggering PEM or prolonged deterioration (relapse).

23	Guideline	6	14	The term ‘noise’ should be replaced with the term ‘sound’ here and for every use of ‘noise’ in the guideline. ‘Noise’ suggests that sound must be loud to a person of normal hearing to be problematic to a person with ME/CFS. This is not the case; quiet sound can be extremely difficult to tolerate for people with ME/CFS with severe sensitivity to sound.
24	Guideline	6	14-15	It should be made clear that exposure to light, sound, touch, movement and extremes of temperature if poorly tolerated can lead to PEM. For those with severe sound sensitivity, exposure to sound can cause rapid and potentially long-term deterioration.
25	Guideline	6	20-21	‘insomnia’ should be added to the bullet point on sleep disturbance.
26	Guideline	6	22-23	‘gastroparesis’ should be added to the bullet point on gastrointestinal difficulties.
27	Guideline	6	26-27	This should be amended to reflect that there are other subtypes of orthostatic intolerance not listed here. Suggested phrasing: 'orthostatic intolerance. People with severe ME/CFS may only be able to be upright for a very short time, if at all, before experiencing symptoms including dizziness, pallor, nausea and vision problems.'
28	Guideline	7	8	This should be amended to include recognition that people with ME/CFS who need wheelchairs will need ones that fully recline, support the whole head and body, and be easily adjustable to change posture to minimise pain.
29	Guideline	7	9-10	The guideline should provide further information on arranging and seeking funding for suitably trained advocates (ideally with experience in ME/CFS) for people with ME/CFS, and acknowledge it takes time for them to get acquainted with the specifics of an individual’s case to advocate effectively for them.
30	Guideline	7	15	The term ‘noise’ should be replaced with the term ‘sound’ here and for every use of ‘noise’ in the guideline. ‘Noise’ suggests that sound must be loud to a person of normal hearing to be problematic to a person with ME/CFS. This is not the case; quiet sound can be extremely difficult to tolerate for people with ME/CFS with severe sensitivity to sound.
31	Guideline	7	16	After line 16, a further bullet point should be added for recognition of the sensitivities to sound and smells experienced by people with severe or very severe ME/CFS in all circumstances, including whenever communicating with or assisting the person with ME/CFS with activities of daily living.
32	Guideline	7	16	After line 16, a further bullet point should be added to include recognition that people with severe or very severe ME/CFS may need to remain in a horizontal or reclined position most or all of the time, and may require special equipment to enable this.
33	Guideline	7	17-21	The guideline should acknowledge that personal care for someone with very severe ME may take more time than standard rates allow for in social care planning and that planned care may not be able to be done on days when the patient is too unwell.
34	Guideline	7	24-26	The guideline should provide further information on arranging and seeking funding for suitably trained advocates (ideally with experience in ME/CFS) for people with ME/CFS, and acknowledge it takes time for them to get acquainted with the specifics of an individual’s case to advocate effectively for them.

35	Guideline	8	5-9	We suggest addition of a bullet point in 1.2.2 stating the person with ME/CFS should keep an activity and symptom diary for review as part of this assessment. This should be compared with premorbid activity levels and may assist with the identification of PEM and so with a diagnosis.
36	Guideline	8	8	Replace with: *'a psychological wellbeing assessment, if indicated or requested by the person with ME/CFS. Do not assume natural reactions to ME/CFS symptoms such as worry or changes in behaviour such as withdrawal from activities are indicators of mental health disorders.*' The term 'psychological wellbeing assessment' should be defined.
37	Guideline	8	10	We suggest the criteria for suspecting ME/CFS could be clarified by providing information on common medical conditions that may result in a similar symptomatology, as this may aid physicians in ruling out such diagnoses and prevent mis-diagnosis with ME/CFS.
38	Guideline	8	11	The word 'persistent' should be deleted due to similarity of 'persistent symptoms' to the term 'persistent physical symptoms' (PPS). The term PPS is often used interchangeably with 'medically unexplained symptoms' to describe physical symptoms for which an explanation has not yet been found, inappropriately implying there is no medical explanation to be uncovered and mental health issues are an underlying factor irrespective of whether they are actually present. Application of these terms may deter physicians from making appropriate referrals and investigations. Further, the wording 'the person has had all of the persistent symptoms' implies that all required symptoms must be present all the time for diagnosis to be made. PEM, by definition is an intermittent symptom related to activity level. Assuming it has to be 'persistent' may lead to missed diagnoses.
39	Guideline	8	16	Should include that specific onset typically follows an infectious illness. Should also acknowledge that some cases have gradual onset; not to specify this may exclude this subset from a diagnosis of ME/CFS, potentially leading to inappropriate management advice and harm to people with gradual onset ME/CFS. The IOM (Institute of Medicine) requirement for specific onset is qualified by 'not lifelong'.
40	Guideline	8	17	(Box 1) Rather than giving an incomplete and misleadingly brief description of the core ME/CFS symptoms in Box 1, with hyperlinks to the definitions which may be ignored, it would be more helpful to provide the full definitions of each term at this crucial stage of the guideline where the terms are first introduced and need to be understood correctly for accurate diagnosis.
41	Guideline	8	17	(Box 1) Fatigability and fatigue: The list of core symptoms, though based on the IOM (Institute of Medicine) criteria, has changed the first criterion from a description that clearly includes both fatigability (described as impairment to engage in former levels of

				activity) and fatigue, as two different features of the first criterion. We recommend adding back fatigue, described as IOM does, as "often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest".
42	Guideline	8	17	(Box 1) PESE/PEM: The term Post-Exertional Symptom Exacerbation (PESE) should not be used. We support the continued use of the well recognised term 'post-exertional malaise' (PEM). There is a strong argument for including the word 'malaise' which has the specific medical meaning of feeling generally very unwell, and describes the experience of PEM well. Guidelines should work with widely accepted terms, rather than inventing new ones. PEM is the term used in international ME/CFS research and it is the term used in a wide range of training and information resources.
43	Guideline	8	17	(Box 1) Unrefreshing sleep: The bullet point on unrefreshing sleep should be revised. It is not clear what is meant by ‘unrefreshing sleep’. The first subcategory of unrefreshing sleep lists symptoms experienced on waking; the second lists types of disordered sleep. It is not clear if symptoms on waking must be worse than normal to qualify as unrefreshing sleep, or if sleep not helping to resolve symptoms of ME/CFS is being mistaken for ‘unrefreshing sleep’. Disordered sleep patterns may lead to increased symptoms on waking, but proper sleep does not lead to people with ME/CFS feeling better. ‘Insomnia’ should be included in ‘broken or shallow sleep, altered sleep pattern or hypersomnia’, as this is a significant symptoms for some people with ME/CFS.
44	Guideline	8	17	(Box 1) Cognitive difficulties: We are deeply concerned that cognitive difficulties are a requirement for suspecting ME/CFS in Box 1. This guideline recommendation is said to be based on the experience of the guideline committee (Evidence Review D, p.51 lines 26-28). The experience of a small committee is not an adequate basis for creating untested criteria. Promotion of cognitive difficulties to a requirement is a significant modification to IOM (Institute of Medicine) criteria, not a slight one (as claimed in Evidence Review D p.49 lines 44-45). It will significantly skew the balance of inclusion/exclusion towards exclusion, preventing a substantial subset of people who do not experience cognitive difficulties from obtaining a rightful diagnosis of ME/CFS, leading to inappropriate management advice and harms.

				We recommend that the IOM criteria should be followed in full, with the fourth listed required symptom being one of either cognitive difficulties or orthostatic intolerance. We would also agree to making the criteria for diagnosis less stringent by moving both cognitive difficulties and orthostatic intolerance to the list of other common symptoms. What we see no justification for, and harm resulting from, is the Committee's decision to make it mandatory for diagnosis that the person reports cognitive difficulties. We do not think it is right to exclude many people who meet internationally recognised ME/CFS criteria from being diagnosed with ME/CFS and getting the support and help they need. We are pleased to see a thorough description of cognitive difficulties with inclusion of subtypes and these should be retained in any amendment to cognitive difficulties in the criteria.
45	Guideline	9	2-16	Should include a bullet point for gastrointestinal symptoms. Nausea is currently only addressed as a symptom of orthostatic intolerance.
46	Guideline	9	17-20	Members support an early provisional diagnosis but there was concern that patients be given information about the likelihood of recovery that is appropriate for the length of illness. Add: *'Ensure that any advice about the likelihood of recovery takes into account the time since onset: recovery rates are initially high but decrease to a lower level over the first two years of illness.'*
47	Guideline	10	1-3	Include recommendation for specialist input for all cases of suspected ME/CFS, since there is evidence of significant misdiagnosis in primary care.
48	Guideline	10	15-21	The advice to people with suspected ME/CFS to rest and not to use more energy than they perceive they have is good and should be retained. We suggest the term 'symptom-contingent pacing' be used throughout the guideline, to convey that activity levels should be judged on current symptoms with the object of avoiding post-exertional malaise.
49	Guideline	10	17-19	Suggested alternative wording: '*Not to use more energy than a level that the person can sustain easily without leading to worsening symptoms, and not to continue increasing activity if symptoms begin to worsen.'* Reasoning: This avoids introducing new patients to a confusing metaphor (energy envelope).
50	Guideline	10	22	People with suspected ME/CFS need to be given information about the likelihood of recovery that is appropriate for the length of their illness. Add to 1.3.2: '*Advise them that the likelihood of recovery decreases as time since onset increases; rates of full recovery are initially high but decrease to a lower level over the first two years of illness.*'
51	Guideline	10	23	The word 'persistent' should be deleted due to similarity of 'persistent symptoms' to the term 'persistent physical symptoms' (PPS). The term PPS is often used interchangeably with 'medically unexplained symptoms' to

				describe physical symptoms for which an explanation has not yet been found, inappropriately implying there is no medical explanation to be uncovered and mental health issues are an underlying factor irrespective of whether they are actually present. Application of these terms may deter physicians from making appropriate referrals and investigations. Further, the wording 'diagnosis can only be confirmed after 3 months of persistent symptoms' implies that all required symptoms must be present all the time for diagnosis to be made. Post Exertional Malaise (PEM), by definition is an intermittent symptom related to activity level. Assuming it has to be 'persistent' may lead to missed diagnoses.
52	Guideline	11	3	We suggest a list of common conditions that should be excluded as part of the diagnostic process and a list of tests that should be carried out be specified, so that GPs have guidance on this for cases where specialist referral is not possible.
53	Guideline	11	5-6	Include that diagnosis should ideally be made by a specialist physician who has up-to-date knowledge of ME/CFS in keeping with this guideline, but acknowledge that the person may not be able to travel to a specialist service for diagnosis, and diagnosis by GP with input from a specialist physician may be appropriate in such cases.
54	Guideline	11	5-6	We agree with early provisional diagnosis. We suggest this recommendation include that investigations should be continued after diagnosis to rule out other possible conditions. A single referral may have a wait time of more than three months, but management in accordance with this guideline should not be delayed if ME/CFS is suspected. *Add: 'Management in accordance with this guideline should not be delayed if ME/CFS is suspected, even if investigations to rule out other conditions continue.'*
55	Guideline	11	6	Wording 'persisted for' implies that symptoms must have been present all the time for diagnosis to be made. Inclusion of this wording may lead to failure to diagnose ME/CFS for many.
56	Guideline	11	7-8	Replace with: *'After a primary care provisional diagnosis,* refer *the person to a consultant working in a relevant biomedical discipline who has specialist knowledge of ME/CFS in accordance with this guideline to carry out any further tests needed to confirm the diagnosis. If the patient agrees, the consultant led team should develop a management plan (medical care plan) with the patient. In severe cases this may require a home visit or other special arrangements.'*
57	Guideline	11	9-12	Not every young person will want a management plan (medical care plan), be able to travel to see a specialist team, or even be able to participate in an evaluation in their own home. Replace with: '*After provisional diagnosis, with the agreement of the child with ME/CFS and their family, or the young person with ME/CFS, refer them to a paediatrician working in a relevant biomedical discipline who has specialist knowledge of ME/CFS in accordance with this guideline to confirm diagnosis and develop a medical care plan (management plan).*'

58	Guideline	11	13	There should be a clear statement in section 1.5 that people with ME/CFS should not be referred to MUS or fatigue clinics for assessment and care planning or at any other stage in the diagnosis, assessment and care of ME/CFS, as these clinics do not specialise in ME/CFS and may take an inappropriate approach which does not adequately take considerations specific to ME/CFS into account. People with ME/CFS should only be referred to pain clinics that have an up-to-date understanding of ME/CFS in keeping with this guideline.
59	Guideline	11	15-16	Why is there an additional requirement for a 'holistic assessment' after diagnosis is made? A proper diagnostic process should include taking a full history and conducting physical exams. Performing a 'holistic assessment' in addition means duplication of history-taking, physical exams and assessments, which may be difficult for people with ME/CFS to achieve and may cause worsening.
60	Guideline	11	15	The guideline should suggest that input for original development of a management plan (medical care plan) should be taken from recent medical notes where possible. Information should be gathered by modes of communication accessible for the person with ME/CFS, e.g., by email, or correspondence by post, enabling them to respond at their own pace. If face-to-face visits are required to enable this home visits should be offered for the moderate, severe and very severe. We also suggest linking to 1.8 'Access to care' in 1.5.1.
61	Guideline	11	15	It should be specified that this assessment should only be carried out by a physician with up-to-date knowledge of ME/CFS in keeping with this guideline.
62	Guideline	11	15	The word 'holistic' should be deleted. It is commonly associated with alternative medicine.
63	Guideline	12	1-2	The words, '*and other causes of physical or emotional stress*' should be deleted. This is already covered by '*anything known to exacerbate symptoms*', so duplicates content. Deletion may also reduce risk of misinterpretation that 'stress' may be a cause or perpetuating factor of ME/CFS.
64	Guideline	12	4	The word 'psychosocial' should be deleted. The wording, '*The impact of symptoms on wellbeing*' is adequate. 'Psychosocial' is a loaded term in the context of ME/CFS. We do not think that formal psychological assessment is relevant unless it is requested or indicated.
65	Guideline	12	10	It should be specified in 1.5.2 that the 'management plan' should be developed by a GP, consultant physician, or specialist nurse who is part of the consultant's team, and they should have up-to-date ME/CFS training in accordance with this guideline. There should be recommendation for ongoing specialist oversight where available but with acknowledgment some people with ME/CFS may prefer or only be able to access assessment and care planning by their GP. People with ME/CFS under a consultant should not be discharged back to their GPs unless requested, to enable continuity of care and prevent repeat re-referral. The guideline should also specify that the person with ME/CFS should have a named contact (per recommendation 1.10.3) who will ideally be a specialist nurse (and not a therapist) with up-to-date training in ME/CFS consistent with this guideline and be the person with ME/CFS should be informed how to contact them.
66	Guideline	12	10	We consider the term 'medical care plan' to be more appropriate than 'management plan'. The former makes it clear that it is a plan to deliver care. The term 'management plan' implies that the person with ME/CFS and their

				condition are to be managed. All uses of 'management plan' throughout the draft guideline should be changed to 'medical care plan'.
67	Guideline	12	25-26	The recommendations referred to as covering symptom management should read '1.11.24-1.11.42' (and not 1.11.27-1.11.50 as they do presently). This would correctly cover the section on 'Managing orthostatic intolerance', which is currently excluded from the range given, and would also correctly remove reference to the section on 'Psychological support', as psychological support should not be offered to manage symptoms of ME/CFS.
68	Guideline	13	2	The words '*The plan should be mutually agreed*' should be deleted. It may contradict the earlier clause '*the person with ME/CFS is in charge of the aims of their management plan*'. Healthcare workers may have unrealistic ideas about what activity levels and types the person with ME/CFS can cope with, meaning development of unsustainable management plans which may result in harm to people with ME/CFS.
69	Guideline	13	9-10	We suggest inclusion of the words '*the person with ME/CFS should be kept informed at all stages of assessment for and development of the management plan (medical care plan) and be provided with copies of written records of these'.*
70	Guideline	13	13	The word 'holistic' should be deleted. It is commonly associated with alternative medicine.
71	Guideline	13	12-13	1.5.5 should include that home visits to collect large amounts of information from people with severe or very severe ME/CFS are unlikely to be successful or safe. Almost all people with ME/CFS would benefit from being given the questions online or in hard copy so they can be completed at their own pace. We also suggest inclusion of a link at 1.5.5 to 1.8 'Access to care'.
72	Guideline	13	14	We appreciate that section 1.6 sets out the major impact of the illness on the lives of people with ME/CFS and makes it clear how important accurate and up-to-date information on financial and social support for people with ME/CFS and their families and carers are.
73	Guideline	13	16-18	'individual or group peer support' may be added to the list of example formats. Our members find interacting with other people with ME/CFS (whether in person or online) a useful means of learning how to cope with the condition.
74	Guideline	14	9-14	We strongly agree information provided to people with ME/CFS and their families/carers should be up-to-date. However, it should also be stated that it must be in accordance with this guideline. It should not be about 'chronic fatigue', or medically unexplained symptoms (MUS), or based on excessively broad diagnostic criteria that excludes post-exertional malaise as a requirement for diagnosis. It should not suggest recovery can be achieved by exercise, increasing activity, changing behaviours or beliefs about the illness, or better stress management. It should not present speculation on cause of ME/CFS as fact.
75	Guideline	14	9-14	Add: '*ME/CFS information prepared prior to this guideline must be reviewed and, if necessary, re-written to ensure compliance with this guideline before it is distributed*'.

76	Guideline	14	16	Delete: ‘that affects everyone differently’. This is true for all medical conditions. Highlighting it here suggests more variability than is the case and may lead to misdiagnoses. Diagnosis requires meeting specific criteria (section 1.2).
77	Guideline	14	16-18	Clarify that while symptoms may fluctuate, overall severity status may deteriorate significantly and rapidly, but overall improvement (when this does take place) usually happens gradually over much longer time periods.
78	Guideline	14	19-21	Delete, as repeats content at lines 16-18 and 22-24. Alternatively, replace ‘often’ with ‘may’ and remission should be qualified with ‘partial’ to clarify that remission may not mean complete remission. I.e., ‘*may involve periods of partial remission and relapse or prolonged deterioration*’. Although the condition can fluctuate, our members report that periods of complete remission are rare, so the current phrasing could be misleading.
79	Guideline	14	22-24	This statement is not correct given that diagnoses are being given before 6 months. Discussion of prognosis for adults and children would be best covered in the same recommendation. Replace with: '*varies in long-term outlook from person to person. Recovery rates decrease with increasing lengths of illness. Recovery rates are initially high but full recovery is rare after two years. The outlook for children and young people tends to be better than in adults*.'
80	Guideline	14	25	Should replace ‘can have’ with ‘has’, i.e., ‘*has a major impact on people’s lives*’, as ME/CFS always has a major impact on people’s lives.
81	Guideline	14	26-27	Should replace ‘may’ with 'will', i.e., '*will need to adjust how they live*’. The use of 'may' underplays the effect of even mild ME, which by diagnostic definition significantly reduces the ability to carry out daily activities. We suggest adding: '*Many people with ME/CFS will need to make significant adjustments to or discontinue their current work or educational commitments.*'
82	Guideline	14	28-29	Lines 28-29 should be deleted. ME/CFS is worsened by cumulative energy expenditure in excess of what can be tolerated. It is therefore incorrect to refer to specific triggers. We are not aware of reliable evidence that childbirth causes a worsening of ME/CFS greater than any similar exertion might, and some women report an improvement during pregnancy or after giving birth.
83	Guideline	14	30-31	The words 'may be self-managed with support and advice' underplays the seriousness of the illness. People with very severe ME/CFS may be completely reliant on others. Replace with: '*has no cure or effective treatments. Energy management (including symptom-contingent pacing) may help to reduce the impact of symptoms*.'
84	Guideline	14	31	Add a bullet point in 1.6.4 to explain that ME/CFS can be worsened by over-exertion and that it is important for the person with ME/CFS to avoid over-exertion for this reason.
85	Guideline	15	1-3	Discussion of prognosis for adults and children would be best covered in the same recommendation. Replace with: '*varies in long-term outlook from person to person. Recovery rates decrease with increasing lengths of illness. Recovery rates are initially high but full recovery is rare after two years. The outlook for children and young people tends to be better than for adults.'*

86	Guideline	15	8	After 1.6.6, add a new recommendation: '*provide appropriate letters and reports to benefits and insurance agencies in support of unemployment and disability benefits and claims. Ensure patients have been recently reviewed so such reports are up to date*.'
87	Guideline	15	16-18	After 1.6.9, add a new recommendation: '*With the consent of the person with ME/CFS, provide information to care agencies about the severity of their symptoms and their specific needs*.'
88	Guideline	16	5	General comment for safeguarding section Move the content of 1.7 Safeguarding ME/CFS to the Section 1.2 Suspecting ME/CFS. The reason safeguarding requires comment in this guideline is because there have been failures on the part of doctors to recognise ME/CFS, and to convey that diagnosis and the implications of it clearly to social services. Therefore, it is an issue of needing to take great care when considering differential diagnoses of mental illness or parental abuse or neglect. The currently separate section on safeguarding may actually contribute to the incorrect suggestion that safeguarding is more likely to be required in ME/CFS than in other chronic illnesses.
89	Guideline	16	5	We appreciate the clear statements in 1.7 that professionals involved in safeguarding should have experience in ME/CFS, that symptoms of severe or very severe ME/CFS may be confused with signs of abuse or neglect, and that response to possible child abuse and neglect should be considered in the same way for children and young people with confirmed or suspected ME/CFS as with any child with a chronic illness or disability.
90	Guideline	16	5	There will need to be substantial retraining of health and social care professionals involved in safeguarding processes for people with ME/CFS. Such training should be in accordance with the recommendations in this guideline.
91	Guideline	16	6-8	Add at the beginning of the recommendation: 'Considerable harm has been caused by mistaking ME/CFS as mental illness, abuse or neglect'. Specify that training and experience should be in accordance with the recommendations in this guideline. Older training and previous experience may be out of date and lead to inaccurate assessments and significant harm to people with ME/CFS..
92	Guideline	16	6-8	The sentence 'Safeguarding assessments in people with confirmed or suspected ME/CFS should be carried out or overseen by health and social care professionals who have training and experience in ME/CFS' can be misread as suggesting everyone with ME/CFS needs a safeguarding assessment. We recommend adding to the beginning of the sentence: 'If abuse or neglect is suspected, ... '
93	Guideline	16	9-11	Replace with this: 'Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of mental illness (including eating disorders) or of abuse or neglect.' We recommend moving section 1.7.2 to before section 1.7.1 to emphasise that this section is about the problems of symptoms of ME/CFS being misinterpreted as safeguarding issues.
94	Guideline	16	12-15	It should be recommended that in the best interests of the person with ME/CFS, where possible, a health or social care professional chosen by the person with ME/CFS be involved in any such assessment.

95	Guideline	16	12-15	Include ensuring that where possible, the person with ME/CFS should have a family member or advocate present for any such assessment.
96	Guideline	16	12-15	Add that health and social care professionals should only have involvement if they understand that ME/CFS is not a psychiatric disorder and that it is not appropriate to reframe the symptoms of ME/CFS as another condition.
97	Guideline	16	12-15	Specify that ‘training and experience in ME/CFS’ must be up-to-date and consistent with this guideline, as inadequately informed health and social care workers may do enormous harm.
98	Guideline	17	8-19	We recommend moving section 1.7.6 to the beginning of the 'children and young people' section, before section 1.7.4. This would help to emphasise that the issue being addressed is misunderstanding of symptoms leading to inappropriate diagnosis of FII and other safeguarding issues.
99	Guideline	17	14-16	Should also cover refusal of assessment for and development of the management plan or declining to restart any part of it. Suggested wording: ‘*declining assessment for and development of a management plan (medical care plan), or disagreeing with, declining, withdrawing from or refusing to restart any part of their management plan (medical care plan), either by the child or young person, or by their parents or carers on their behalf’*
100	Guideline	17	19	Should include not participating in home schooling.
101	Guideline	17	20	Access to Care: Overall section 1.8 is helpful. We are concerned that there will be a wide gap between what is recommended and what happens in practice. We recommend that the importance of this section be emphasised in the guideline. Many people with ME/CFS currently have no access to current medical services, not just for their ME/CFS symptoms, but for other serious comorbidities and even for emergencies, because of insurmountable barriers to access.
102	Guideline	17	20	Add: We recommend that an NHS endorsed ME/CFS passport be developed that sets out the requirements of the individual patient during health care interactions. Information about the patient's requirements should be included in their medical notes and made clear to all clinical and hospital staff who deal with them.
103	Guideline	17	21	'people with ME/CFS...' Add: 'and those awaiting possible ME/CFS diagnosis'.
104	Guideline	18	1	Add: 'discussing any proposed referral with the person with ME/CFS before making it and considering related access needs'
105	Guideline	18	6	replace 'noise' with 'sound (speak quietly)' It is not just loud sound that affects people with ME/CFS.
106	Guideline	18	8-9	care flexibility: Add email, and letter as options. Add providing a quiet, dimmable separate place to lie down, and option to wait in car, while awaiting appointment. Make it clear that this applies for all severity levels of ME/CFS. Add: People with ME/CFS who live alone and have no car may need assistance with arranging safe and manageable transport to and from appointments, or home visits.
107	Guideline	18	9	Add 'be aware of the patient's cognitive problems and physical fatigability during consultations. Make accommodations for this, for example by making use of written and electronic communication before and after a

				consultation. Allow patients to bring notes prepared in advance to be entered in their medical records. For patients with severe ME/CFS and others who request it, provide a written summary of all consultations.'
108	Guideline	18	15	change 'fear of relapse' to 'likelihood of triggering PEM or deterioration', as 'fears' are likely to be rational and founded in experience (see Evidence Review G, p.326, lines 45-47).
109	Guideline	18	18	Add an extra bullet point: 'The person is likely to have prepared with pre-emptive rest in order to be able to attend an appointment.'
110	Guideline	18	19	**People with severe or very severe ME/CFS** This section should also be applied to people with moderate ME/CFS who are largely housebound and have similar problems with access to and use of services.
111	Guideline	18	23	add: communication with a carer on the person with ME/CFS's behalf (with their agreement). add: communications that are not real-time (such as texts and emails) may be particularly useful for this group.
112	Guideline	19	7	replace 'noise' with 'sound', as even quiet sounds may be a problem for some people with ME/CFS.
113	Guideline	19	13-16	add: where needed arrange ambulance travel to and from hospital or hospital stretcher between car and ward.
114	Guideline	19	19	Add bullet points to Section 1.8.6: - 'minimise disruption to the patient's sleep, where possible accommodate the patient's sleep schedule. - Ensure nursing and other appropriate staff are apprised of needs re assistance with washing, toileting, and feeding when required. Some people with ME/CFS without having the outward appearance of needing support, may need assistance.
115	Guideline	19	20	'aim to provide a single room where possible' is not sufficient. People with severe or very severe ME/CFS are likely to deteriorate in a hospital ward. For these people, a single room is not a 'nice to have' but a need; they are likely to choose not to be in hospital if their need for a quiet low-stimulus room cannot be met. Add: people with very severe ME may be unable to communicate their needs, with hospital staff. Provision should be made for their carer to stay with them in hospital to assist staff in ensuring care is provided to minimise symptom exacerbation.
116	Guideline	19	21-29	This section needs to make it clear that ordinary minor stimuli may be very painful and may lead to prolonged symptom worsening. line 25: add: 'and being aware that physical examinations, tests and scans can cause severe pain or deterioration. Ensure the patient is listened to and provide any needed accommodations, sedation or pain relief. line 26: 'lights dimmed' add 'and off whenever possible'. line 27: Change 'noise' to 'sound' line 29: Change 'strong smells' to 'smells'.
117	Guideline	20	6-7	'access to outside space' Some people with ME/CFS may have great difficulty accessing public spaces due to the impact of sounds and

				social contact, and so a private outside space such as a garden may be important for well-being and health maintenance e.g. exposure to sunlight.
118	Guideline	20	9	'glare from lights' change to 'reduce light levels'.
119	Guideline	20	10	'loud noise' change to 'sound at levels that cause them problems' Add 'Exposure to sensory stimuli, at levels healthy people can easily tolerate, is not only difficult to cope with at the time, but can lead to rapid physical and/or cognitive deterioration.'
120	Guideline	20	11	Add: Accommodation not at ground level will usually present difficulties for people with ME/CFS, particularly for people using wheelchairs, and especially reclining wheelchairs. Even if lifts are large enough, sounds and vibrations can be troublesome for people with severe sensitivities and may not be available during an emergency evacuation.
121	Guideline	20	17-18	'families and carers ...' Add: 'and care agencies and their staff' It should not be assumed that people with ME/CFS have families or consistent carers. Add: The medical team should liaise with social services and care agencies to ensure they have up to date written information on the individual's care needs, including extra time needed for some care tasks. Add: Ensure the person with severe or very severe ME has access to appropriately trained advocacy services to help them access the medical, care, practical support and financial support they need. Add: Consider, where appropriate, referral for respite care or palliative care services. In very severe cases it may be appropriate to consult a palliative care specialist.
122	Guideline	20	20-22	Add: For patients who don't yet have a management plan (medical care plan), do not delay access to aids and appliances until the plan is completed.
123	Guideline	20	29-30	delete 'taking into account risks and benefits'. An evaluation of risks and benefits should be done for any recommendation for aids and adaptations, but its explicit mention here seems to reinforce the mistaken view that the use of aids can lead to a reduced incentive to be active.
124	Guideline	20	30	Add: Orthostatic intolerance may mean that some people with ME/CFS require fully tilting and reclining wheelchairs and chairs.
125	Guideline	21	4-5	Many people with ME/CFS will not be able to return to work or education at all, or may gradually deteriorate due to doing more than can be sustained. Therefore the advice needs to be realistic. People with ME/CFS need to be made aware that recovery is most likely in the first two years. After that time, there is only a very small probability of a full recovery and plans to return to work may be unrealistic. Clarity about this will help the patient and their family plan appropriately. Add bullet point to 1.9.1: - *'Ensure the person has information on how to access advice on the financial implications of, and their rights in relation to, changes to employment arrangements including stopping and starting work, and reducing hours.'*

126	Guideline	21	11-14	Not all patients have, are able to get, or want, management plans. Not all information in a management plan should be shared with an employer, school or support service. Information provided to third parties needs to be limited to that which is directly relevant. Replace with '*Offer to liaise on the person's behalf (with their informed consent) with employers, education providers and support services. Give them information about ME/CFS, and relevant aspects of the person's illness, including any adjustments required*.' Add bullet points to 1.9.2: - '*Ensure the person with ME/CFS is included in all decision making with employers, apprised of the content of all discussion, and provided with copies of all correspondence relating to them.'* - *'communications between a person's employer or education provider, health and social care professionals, and training and education services must respect patient confidentiality and comply with relevant data protection law at all times'*
127	Guideline	22	1-2	We are concerned about the statement 'discuss the child or young person’s management plan'. This may include information not appropriately shared with people other than their medical team. Only relevant parts should be discussed, and only with informed consent.
128	Guideline	22	3-5	Add 3 bullets points to 1.9.4: - *'The child or young person's health needs to take priority over education, and there may be times when it is best to step away from education to allow the child to rest without pressure of trying to keep up with work. Flexibility needs to include complete breaks during times of severe illness.'* - '*When relevant, health and social care professionals should explain to training and education services that some children and young people with ME/CFS are not only unable to attend school but may have significantly reduced ability to engage in online or home schooling, or may need to discontinue schooling of any form altogether on either a short or long-term basis*.' - *'Ensure the young person with ME/CFS is included in all decision making with education providers, apprised of the content of all discussion, and provided with copies of all correspondence relating to them.'*
129	Guideline	22	10-12	This is both too prescriptive and unrealistic. Suggested replacement version: *'Advise children and young people with ME/CFS (and their parents and carers) that:* *- The first priority should be to avoid any deterioration of health while achieving some quality of life*

				- they should be free to choose which aspects of education, home and family life and social activities they prefer to spend their very limited energy on, without pressure to conform to social norms expected of heathy children. For some this may mean withdrawing from education. There should be no pressure to return to education until their health allows *- recognise cognitive problems that are part of ME/CFS may make some subjects too difficult for the child to study. Flexibility on subject choices is important.'*
130	Guideline	22	13	**Section 1.10 Multidisciplinary care – Overall Comment** We suggest changing the heading of section 1.10 from 'Multidisciplinary care' to 'Coordination of care', as referred to in Evidence Review I (p.23 line 46) and to reflect use in the NICE clinical guideline, 'Multiple sclerosis in adults: management' (CG186). The current section 1.10 heading is misleading as it implies all people with ME/CFS need multidisciplinary care. Many people with ME/CFS will neither need nor want multidisciplinary care, having no need for physiotherapy, occupational therapy, psychological therapy or dietary advice. Many will be well served by consultant diagnosis, and ongoing help and review as needed by a specialist nurse and GP. We are pleased the committee has recognised the importance of a single point of contact to coordinate care for people with ME/CFS in order to mitigate the risk of contact and appointments with several different people impacting *'negatively on the person's health potentially worsening symptoms'* (Evidence Review I p.21 lines 26-29; pp.24-25). However, we disagree with the committee's decision not to specify professions that ought to make up the specialist team (Evidence Review I p.23 lines 26-30), as we consider this will lead to people with ME/CFS undergoing multiple appointments with different healthcare professionals (HCPs), regardless of coordination of care by a named contact. It also risks issues being dealt with by therapists of the wrong specialism, risking mismanagement and harms to people with ME/CFS. There is the further concern that someone allocated, for example, a psychologist, as their point of contact, will avoid further use of the service even when they need help, because they do not see the relevance of psychology to their need. To remedy this risk of worsening for people with ME/CFS, we recommend the guideline specify a streamlined specialist team, led by a consultant of a suitable biomedical discipline with specialist knowledge of ME/CFS, who would confirm diagnosis, order appropriate tests and referrals if needed and oversee care. Specialist nurses with up-to-date training consistent with this guideline would then fulfil the role of main point of contact for the person

				with ME/CFS and provide comprehensive support and care for most issues for which the person with ME/CFS may seek input. This would more closely mirror the NICE guideline for multiple sclerosis (CG186), in which a consultant of appropriate discipline (neurologist) and MS specialist nurses are specified to form part of the team. Rationale: The evidence for a multidisciplinary approach to care in ME/CFS is unacceptably low, with only two studies included on the basis they were the only evidence despite not comparing different multidisciplinary teams (MDTs) (Evidence Review I, p.9). Both were of low to very low-quality evidence (Evidence Review I, p.22 line 1). The quantitative evidence was stated to be limited and thus the cost-effectiveness of ME/CFS specialist MDTs uncertain (Evidence Review I, p.25, lines 26-27). One cost-utility analysis found multidisciplinary rehabilitation (physical therapist, occupational therapist, psychologist and social worker) not to be cost effective compared to CBT (ICER £106,000 per QALY gained. Evidence Review I, p.20). It is acknowledged that cost-effectiveness is *'likely to depend on the staff-mix in the team and the therapies offered.'* (Evidence Review I, p.25 lines 27-28.) In light of the dearth of effectiveness and cost-effectiveness data, it is therefore hard to understand the leap of logic made in the following statement: *'The exact cost effectiveness of a specialist team is uncertain, but the committee were convinced that their provision would be a good use of NHS resources, leading to faster access to appropriate care and substantially better patient outcomes for people with ME/CFS.'* (Evidence Review I, p.25 line 48 - p.26 lines 1-3.) We believe the model of care we propose would by comparison be streamlined and cost-effective. A specialist ME/CFS nurse would be able to provide competent care spanning a significant number of the areas of expertise specified at 1.10.1 (also Evidence Review I, p.26, lines 11-20), and would therefore be able to provide post-diagnosis support and education on a wide range of issues, including energy management, Post Exertional Malaise (PEM) and prolonged deterioration (flares and relapses), symptom management (including medication review), dietary and mobility issues, and be able to provide informal support for emotional wellbeing (See Evidence Review G, p.325, lines 5-9 re importance of someone being available to talk to if help is needed as a form of safeguard). They can support the person with ME/CFS to learn the skills and strategies to self-manage effectively, and provide support if the person with ME/CFS overexerts themselves and experiences worsening (Re importance of these, see Evidence Review G, p.322, lines 33-35, 42-43). Nurses would be able to provide such support by phone, email or home visit and deal with multiple issues in one interaction. In contrast, therapists from various disciplines such as CBT, physiotherapy and occupational therapy, would be

				hampered by the narrowness of their field, and would be unable to fulfil such a role without exceeding the bounds of their expertise. The provision of care and support by a specialist nurse as main point of contact would therefore reduce risk of worsening to people with ME/CFS by virtue of multiple appointments with multiple HCPs and inappropriate management advice, and would be comparatively cost-effective. We agree with the statement in Evidence Review I that most people with ME/CFS will only require a few elements of the areas of expertise specified and only at specific points in time (p.26 line 21). We think early, accurate diagnosis by a consultant with up-to-date knowledge of ME/CFS combined with specialist nurse post-diagnosis support will field most of these elements and reduce the extent and range of healthcare provision required downstream. Provision of care: Such provision would allow for continuity of care and for the specialist nurse to familiarise themselves with the individual circumstances of the person with ME/CFS, as recommended in NICE clinical guideline 'Patient experience in adult NHS services' (CG138). People with mild or moderate ME/CFS may prefer their GP to provide ongoing care or may choose to continue to consult the specialist nurse. People with severe to very severe ME/CFS, are likely to need to continue to be cared for by the specialist team, in conjunction with their GP. Where the person with ME/CFS is referred to a different specialism for investigation of symptoms, the consultant would explain the limitations and particular needs of the person with ME/CFS so that these can be accommodated. Access to specialist services will be difficult for many patients either geographically or because they are too sick to travel. Provision should be made for phone and online access, and home visits by the specialist nurse. In keeping with the Multiple Sclerosis (MS) guideline (CG186) and absence of reliable evidence for CBT to cure, treat or support to manage the symptoms of ME/CFS (Evidence Review G, pp.72-119, p. 318 line 23), we do not think the specialist team should be specified to include CBT therapists. Any qualitative evidence that some people find CBT helpful appears to be largely based on the non-specific skills of a good listener who has rapport with and believes the patient, and whom the patient feels they can contact for support if needed, not on the particular modality of psychological support. (Non-specific benefits of CBT noted in Evidence Review G, p.324 lines 41-43).

				Such elements of care can be provided by an empathic specialist nurse. For those needing further emotional support, access can be provided to a psychological therapist. We strongly recommend it be specified that specialist teams should **not** be led by a mental health specialist, psychiatrist, psychologist, or psychological therapist. We regard stating this in the guideline to be necessary as the draft guideline recommendations represent a significant departure from the 2007 NICE guideline (CG53), on which most current services are based. Their service model is no longer appropriate now that GET and directive CBT that is intended to treat ME/CFS are specifically excluded from the guideline.
131	Guideline	22	13	**Question 1 (From this form)** **Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** **Re-orientation of clinical care teams** With the recognition that the CBT and physical rehabilitation approaches are ineffective, the work of existing ME/CFS clinics must change. It is no longer appropriate for ME/CFS clinics to be managed or run by teams trained in CBT, psychotherapy, health psychology, psychiatry or occupational therapy. There is no need for therapists to provide individual and group courses of multiple sessions based on a psychological and behavioural model. These will need to be closed down as no longer fit for purpose, and their staff redeployed. New physician led medically focused teams will need to be set up, modelled on, and possibly in some instances sharing some staff and facilities with, those provided for other chronic disabling physical diseases such as multiple sclerosis and Parkinson's disease, with specialist nurses whose skill set better qualifies them to assist ME/CFS patients with managing their condition including both energy management, symptom monitoring and treatment, as well as helping with arranging appropriate assistance for work, education, financial, social and personal care needs. Specialist services such as physiotherapy for those who need them will also need to be available. **Increasing expertise in ME/CFS** Training of these new teams will need to be led by people with experience of working with people with ME/CFS in a manner which is fully in accordance with the new guideline. There is likely to be very limited availability of such trainers. It would be completely inappropriate for the training to be led by current providers of services based on the old guideline. **A transition phase**

				The transition to the new approach to ME/CFS is likely to be a challenging time for GPs too. They may have long-term patients who understand the implication of the new guidelines in much more detail than they do, and have high expectations that everything will change immediately. They will also encounter patients whom they need to diagnose with ME/CFS, but then not quite know what to do with them – 10-minute appointments aren't suitable for helping new patients learn even the basics of energy management, let alone how to cope with all the other aspects of the condition. Clinical Commissioning Groups (CCGs) will need to plan the transition phase, including support for GPs needing to manage new patients without a ready-made network of clinics or an experienced consultant to manage patients with more severe symptoms. Getting a specialist nurse service up and running quickly, with nurses fully trained in accordance with the new guideline, under the supervision of physicians with up to date knowledge of ME/CFS and the guideline, should be prioritised, as should the provision of up to date materials for patients about ME/CFS. **Care of people with ME/CFS who have given up on the health system** Past users of clinics based on the old CBT/GET treatments should be informed of the new approach to ME/CFS. This could allow those patients who have avoided interacting with NHS services to benefit from the improvements recommended by the new guidelines. Just as with any medication that is withdrawn, the NHS has a responsibility to recall patients for a review and transfer to the new medical care approach. **Improved care of people with severe and very severe ME/CFS** There needs to be a suite of services including specialist nurses delivering care by email, text or phone and able to advocate for their patients; as well as mobile medical services delivering care to the person's home. There is a need for specialist high dependency housing for the more severely affected patients. Nursing homes are rarely suitable, as the most severely affected patients have severe sensory sensitivities and cannot be adequately shielded in a nursing home. Similarly, hospitals should have provision for appropriate sensory shielded single rooms for severely affected ME/CFS patients who need inpatient treatment and care. **Coordinated management and monitoring** Provision of new services compliant with the new guideline will need to be monitored closely by a national body set up for the purpose, using a robust system of compliance checks and quality control and with power to close down and replace inadequate services. There will also need to be a requirement for harms monitoring by these new services going forward and parity of harms monitoring for non-pharmacological approaches to condition management. If trust is to be restored, wholesale change is needed, including new medically oriented teams and rigorous monitoring of the new services.

132	Guideline	22	13	**Question 2 (From this form)** **Would implementation of any of the draft recommendations have significant cost implications?** Using health and social care professionals who have good knowledge of the reality of ME/CFS (especially for those with moderate to very severe ME/CFS), should halt the problem of disabling symptoms being mistaken for signs of abuse, neglect or mental incapacity. This will result in significant cost and resource savings relating to inappropriate child care proceedings or sectioning of adults who are unable to eat or function due to their severe symptoms. There will need to be initial significant redeployment and retraining as the professions employed in ME/CFS teams are reoriented away from a psychotherapeutic and behavioural model to a medical and energy management model. This will involve some initial costs in redeploying existing staff and recruiting and training new staff. Investment in useful care of people with ME/CFS is fully justified on the basis of the severity and long term nature of ME/CFS. It should, in the long run, save NHS money that has, until now, been wasted on poorly co-ordinated diagnostic processes and often lengthy and ineffective therapies.
133	Guideline	22	21	Delete this line. There is no evidence that patients with ME/CFS have emotional needs as part of their core condition any more than those with other chronic disabling diseases have. Specifying this in the guideline seems to perpetuate the myth that people with ME/CFS are particularly emotionally susceptible, or need help with sexual relationships in a way that is not specified in, for example, the Multiple Sclerosis (MS) guideline.
134	Guideline	23	5-6	Providing they would not prefer a GP to oversee their care, we recommend that people with ME/CFS of all severity levels should remain under the overall management of a consultant, with the GP and/or specialist nurse providing services as required. Very few GPs have the time or knowledge to provide helpful input either in daily management, or in dealing with severe cases. The specialist nurse is likely to have much more knowledge of ME/CFS than the GP, and would be accessible by phone, email or home visit and provide vital liaison with the consultant.
135	Guideline	23	7-10	We support the need for a named contact and think this should be specified as someone with a medical, not a therapy, specialism, likely best served by a specialist nurse, as is provided for other chronic disabling diseases.
136	Guideline	24	4-5	We agree with this statement and its inclusion in the guideline.
137	Guideline	24	7	We suggest substantial revision of subsection 1.11.2 to incorporate the following: '[Energy management]:

				1. Is not curative and should not be expected to result in an increase in capacity for activity over time; *2. Is a self-management strategy for people with ME/CFS that involves:* *a. limiting activity to minimise symptoms, primarily PEM* *b. reserving capacity for activities that matter most to the person with ME/CFS;* *3. Takes into consideration the cumulative effects of all activity (both physical and cognitive) and the mitigating effects of rest;* *4. Recognises that each person has a different and fluctuating energy limit, and they are the best judge of their own limits (lines 16-17);* *5. does not involve undertaking the same amount of activity every day, as to avoid PEM activity levels should be adjusted according to symptoms and the need for pre-emptive rest;* *6. requires the person learn from experience to identify a level of activity that is normally safe, relationships between levels of activity and symptoms, and warning signs they should rest;* *7. can include help from a healthcare professional to recognise relationships between levels of activity and symptoms, particularly for children and young people who may find it harder to judge their limits and can overreach them;* *8. Utilises symptom-contingent pacing to avoid PEM, whereby the person adjusts activity levels based on how they feel;* *9. does not have increasing activity as its objective, even in flexible increments;* *10. can be difficult due to symptom fluctuation and as not all energy demands are predictable;* *11. requires that the person has requisite support, and has living and (if appropriate) work/education environments where the required actions such as limiting activity, pausing tasks and resting can occur.* *12. is not based on any hypothesis about the cause of ME/CFS,* as no cause of ME/CFS has been established.
138	Guideline	24	11-12	The person with ME/CFS will have the most insight as to how they are impacted by activity. There is no need to say of a self-management strategy that the person themselves leads it, and, after the person with ME/CFS has learned the principles, there may not be a need for the involvement of a health professional. Replace with: *'is a self-management strategy for people with ME/CFS that involves:* *a. limiting activity to minimise symptoms, primarily PEM;* *b. reserving capacity for activities that matter most to the person with ME/CFS.'*
139	Guideline	24	13	Replace with: *'takes into consideration the cumulative affects of all activity (both physical and cognitive) and the mitigating effects of rest.'*
140	Guideline	24	14-15	Metaphors like 'energy envelope' may confuse readers and introduce untested terminology that will be unfamiliar to healthcare professionals (HCPs). It is better to convey in plain language that 'energy management' can help

				people to gauge how to avoid over-exerting themselves to reduce occurrence of PEM. We suggest use of the term 'symptom-contingent pacing' to convey in plain language that activity levels should be judged on current symptoms and the likely impact of activity on these with the object of avoiding PEM. This term can be clearly contrasted with potentially harmful forms of pacing, such as schedule-contingent or activity-contingent pacing. Including explanations of these terms in the guideline may go some way to address the issue raised by the Committee of the range of interpretations and lack of a standard definition for the term 'pacing' (Evidence Review G, p.322 lines 5-11). See https://www.physiosforme.com/pacing for information on symptom-contingent pacing. Replace with: '*[Energy management] does not involve undertaking the same amount of activity every day, as in order to avoid PEM, activity levels should be adjusted according to symptoms and the need for pre-emptive rest.'*
141	Guideline	24	18-20	It is not realistic to expect a healthcare professional to be on hand to recognise when a person with ME/CFS is approaching their limit. The aim of any professional input should be to equip the person (and family if necessary) with knowledge for self-management. Replace with : • *requires the person learn from experience to identify a level of activity that is normally safe, relationships between levels of activity and symptoms, and warning signs they should rest;* • *can include help from a healthcare professional to recognise relationships between levels of activity and symptoms, particularly for children and young people who may find it harder to judge their limits and can overreach them;*
142	Guideline	24	21-24	Should be deleted and replaced with an explanation of the concept of symptom-contingent pacing, whereby the person with ME/CFS controls their activity level to minimise Post Exertional Malaise (PEM) and the symptoms of ME/CFS. There is no evidence that increasing activity leads to improvement in people with ME/CFS. 'Progression' when symptoms are improved may still instigate PEM or prolonged deterioration (relapse). 'Pull back' is vague and does not convey the extent of reduction that may be needed. Replace with: • *'Utilises symptom-contingent pacing to avoid PEM, whereby the person adjusts activity levels based on how they feel;* • *does not have increasing activity as its objective, even in flexible increments;;*

				- *can be difficult due to symptom fluctuation and as not all energy demands are predictable;* - *requires that the person has requisite support, and has living and (if appropriate) work/education environments where the required actions such as limiting activity, pausing tasks and resting can occur.'*
143	Guideline	25	1-2	Should be deleted. There is no evidence that energy management results in an increase in activity levels over time, or even stabilises the illness.
144	Guideline	25	3	If such a statement is included, it should be more encompassing since there are a number of unevidenced and harmful hypotheses on cause that may be invoked in connection with energy management. Suggested wording: '*[Energy management] is not based on any hypothesis about the cause of ME/CFS, as no cause of ME/CFS has been established.*'
145	Guideline	25	4-14	In its current form, 1.11.3 focuses on the healthcare professional (HCP) extracting information and delivering plans. Explicit mention of practical assistance on matters like helping the person to consider stopping or reducing work/school and helping them to implement any decisions they make is missing. These are things that will have significant impact on the person with ME/CFS' health and quality of life and should happen before any formal energy management planning. There is no point, for example, making an energy management plan for the situation of the person working full-time if, with some discussion, the person would have decided they needed to be working part-time. We suggest insertion of a new recommendation between 1.11.2 and 1.11.3 on information about energy management that should be discussed with the person with ME/CFS. Suggested wording and points for inclusion: '*Provide the person with ME/CFS with information from reliable sources about energy management (including 'symptom-contingent pacing')*. Discuss the following with them: *1. Their current activity and rest pattern and symptoms. This may be helped by the person keeping a symptom and activity diary in advance of the consultation;* *2. Planning for increased flexibility to allow increased rest and reduced activity. This may include stopping or reducing work/school or ensuring there are suitable places for scheduled rests;* *3. Communicating with friends and family re how best they can provide support;* *4. Finding ways to reduce daily activity whilst maintaining quality of life, e.g., delegating tasks, ceasing low priority activities, utilising adaptations to reduce exertion (mobility aids, Blue Badge, working or schooling from home);* *5. reducing time in high energy demanding environments such as places that are noisy/bright (or using aids such as noise cancelling headphones or dark glasses);* *6. Planning responses to Post Exertional Malaise (PEM) and longer deterioration;*

				7. Information on peer support; *8. Assistance for friends and family who may need to adapt to these changes.'*
146	Guideline	25	4-14	Not all people with ME/CFS will want or need an energy management plan, and many people with ME/CFS would benefit more from advice from healthcare professionals (HCPs) that enables them to better cope with ME/CFS, reduce activity, access aids and get in touch with patient organisations, than from focus on assessments to create energy management plans. Energy management plans place additional restrictions on already constrained lives; creating an environment where they can be followed is an activity in itself. For people with mild and moderate ME/CFS, plans are highly likely to be abandoned for more pragmatic approaches (see Evidence Review G p.323 lines 8-10), possibly leaving people feeling that they have failed. Members of our forum found the ambitious daily schedule approach of GetSetJulie for example, patronising and unworkable. Energy management planning may be of more relevance to people with severe or very severe ME/CFS, who may require highly predictable routines to prevent worsening from unpredictable energy expenditure. We suggest insertion of a new recommendation between 1.11.2 and 1.11.3 recognising the agency of people with ME/CFS in deciding whether they want or need an energy management plan. Suggested wording and points for inclusion: 'Recognise that: • *many people with ME/CFS will not want, require or even benefit from an energy management plan and ongoing professional assistance with energy management, particularly if initial discussions about energy management are done well and good resources are provided;* • *some people with ME/CFS may not be able to decrease activity levels to a level that usually prevents PEM without additional practical support and care, or at all. In these cases, securing the support and care should take priority over completing an energy management plan;* • *the person with ME/CFS should be able to choose whether to have an energy management plan or not, or to stop or restart an energy management planning process.'*
147	Guideline	25	4-6	The words 'goals' and 'expectations' though qualified with 'realistic' create an expectation goals will be set and worked towards. This may cause harm either by assuming the person with ME/CFS should increase activity to

				achieve a goal or by creating a sense of failure if they cannot. Further, some people may not want or need a management plan. There is no reliable evidence for 'benefits in setting of goals'. In Evidence Review G (p.336, lines 23-35), it is acknowledged that rigid or unrealistic goals can lead to deterioration and feelings of pressure and blame. A goal that is unrealistic or rigid to a person with ME/CFS may seem achievable to a healthcare professional (HCP), leading to conflict and feelings of pressure and blame. Suggested replacement wording: *'If the person with ME/CFS would like an energy management plan, discuss and record the person's:'*
148	Guideline	25	4-14	We suggest addition of a bullet point for the sensory impact of the person with ME/CFS' home and (if relevant) work/school environments, including light and sound exposure. Suggested wording: '*sensory sensitivities including light and sound exposure at home and work or school if relevant'*
149	Guideline	25	4-14	We suggest addition of a bullet point that the plan should cover responses to a deterioration of symptoms. Suggested wording: *'ability to recognise and appropriately manage PEM and periods of longer deterioration'*
150	Guideline	25	9	Add 'and whether the person has or needs help.'
151	Guideline	25	15-22	Recommendation 1.11.4 is too oriented to forward planning of activities, and makes no mention of taking notice of symptoms. It is based on the assumption the patient knows their 'energy envelope', a term we have advised against using, and something many people will find difficult to estimate. The words 'as the first step' should be deleted. Replace section 1.11.4 with: *If the person wishes, help them make an energy management plan. This notes how they will manage periods of rest, activity and pre-emptive rest. Ensure that any plan is flexible so the patient can be guided by their symptoms to take sufficient rest breaks during activities, and to reduce activity and rest more if symptoms worsen.*
152	Guideline	25	23-24	Replace with: *'During periodic care reviews, the person with ME/CFS should be asked about their energy management and the frequency of PEM.*'
153	Guideline	25	25-26	This clause should include that reducing activity should be advised if Post Exertional Malaise (PEM) is present and there should be recognition of the effect on function and support needs of PEM or prolonged deterioration (relapse). Most people with ME/CFS have symptoms most of the time and regularly have fluctuations in daily energy levels. The words '*reduce their activity if increasing it triggers symptoms*' implies that people with ME/CFS should be increasing activity.

				Replace lines 25-26 with: *'Advise people with ME/CFS to reduce their activity if their symptoms worsen or PEM is present. Discuss what support they may need to reduce their activity.* *If they are feeling better, they may naturally want to do more, but all increasing should be done gradually to avoid PEM or deterioration. Increased activity may appear to be sustainable for a few days or weeks, but may lead to prolonged deterioration (relapse). Any increase should be small, and not further increased unless activity at that new level can be sustained along with the improvement in symptoms maintained for weeks.'*
154	Guideline	25	27-29	To take into account not all people with ME/CFS will want or need to track activity and symptoms, we suggest the alternative wording: '*Some people with ME/CFS may find it useful to track activity and symptoms to understand patterns, especially early in the illness. Tools such as activity trackers, heart rate monitors, apps and diaries may help with this.*' See Evidence Review G (p.336 lines 36-42), where potential harms of increased burden of tracking is acknowledged.
155	Guideline	26	1-7	Recommendation 1.11.8 currently assumes that people with ME/CFS must have professional assistance in the circumstances specified. The guideline should make clear that referrals must always be contingent on informed consent based on the person with ME/CFS genuinely wanting the assistance. Replace with: *'If a person with ME/CFS wants assistance:* • *with energy management, including support developing an energy management plan; or* • *to access and use energy-saving tools and mobility aids.* *refer them to a physiotherapist, occupational therapist, or specialist nurse who has up-to-date training in ME/CFS management that is in accordance with this guideline.'* If a person has had '*reduced physical activity or mobility levels for a long time*' but is managing their illness well, we do not see what is to be achieved by referral. People with ME/CFS who start to improve are likely to be able to successfully increase activity naturally on their own. Referral may be of use to people who have been largely immobile for a long period, but a clause addressing this should be much more carefully worded and consider limitations of people with severe or very severe ME/CFS, to whom it will mostly apply.
156	Guideline	26	9-11	Subject to informed consent and genuinely wanting referral, any person with ME/CFS, regardless of severity level, who would like assistance with energy management or creating an energy management plan should be referred to a specialist physiotherapist, occupational therapist or specialist nurse with up-to-date training in ME/CFS consistent with this guideline. An ill-informed healthcare professional (HCP) can do much greater harm than the

				absence of a formal energy management plan. A person with ME/CFS may find their activity affected by other symptoms than fatigability, such as orthostatic intolerance, pain and sleep problems which need to be managed in conjunction with energy management. A specialist nurse would be best qualified to see the full picture. If retained, 1.11.9 should link to 1.8 Access to care.
157	Guideline	26	12-15	This clause should be revised. The words ‘when agreeing’ are not appropriate, as they suggest compromise where parties differ, leading to the person with ME/CFS ‘agreeing’ to do more than they are able without worsening. Changes in activity for mild and moderate cases may also need to be small and slow or may not be possible; the clause implies this is only the case for severe and very severe.
158	Guideline	26	15	Include a recommendation after 1.11.10 that includes the following: *'Energy management planning for people with severe or very severe ME/CFS requires a high level of specialist knowledge. Balancing a need for social connection and quality of life with the fact that even a short time on an electronic device or a small amount of talking can have a significant impact on symptoms is difficult. Health professionals who have not done energy planning for people with ME/CFS who are severely or very severely affected must first get advice from others who have.* *'Recognise that deterioration in functioning can result in the person needing a very high level of care. The energy management plan should set out what will be done when this happens, including how the extra support will be provided.'*
159	Guideline	26	16	We think the subsection, 'Physical maintenance' is a helpful, practical subsection that can make a difference to the well-being of people with ME/CFS and their carers.
160	Guideline	26	17-22	Include dental health in 1.11.11. Dental consultations present problems of travel, being upright for wait time and coping with examination for people with ME/CFS.
161	Guideline	26	17-18	After the first sentence, we suggest adding: *‘Any proposal for physical maintenance needs to be based on a realistic assessment of the person's ability to sustain the action. The possibility of causing PEM, consequent reduction in function and lowered PEM threshold, alongside displacement of essential activities should be weighed carefully against likely benefits of any physical maintenance.'*
162	Guideline	26	17-22	We suggest inclusion of sensible examples of appropriate physical maintenance. Eg., ‘*Muscle flexibility e.g. gentle stretches in bed*.’
163	Guideline	27	20	Comment on the subsection 'Physical activity': We are pleased the committee recognises the high risk of bias presented by open label trials with subjective outcome measures, the impact of this on interpreting evidence, and that there is no good quality evidence that exercise or activity programmes are effective treatments or cures for ME/CFS (Evidence Review G, pp. 137-165,

				334-335; Draft guideline: Rationale and impact, p.63 lines 7-8). However, on the same basis, there should be no recommendation to offer physical activity programmes in this guideline. Therefore, the content of the subsection on physical activity should be deleted and replaced with a clear statement outlining types of activity and exercise programmes that should **not** be offered to people with ME/CFS. Rationale: There is no reliable evidence that physical activity programmes are effective in treating or managing ME/CFS, or increasing function or tolerance to activity in people with ME/CFS (which may be viewed as treating). Evidence quality for all GET and other exercise intervention studies was judged to be low or very low, with inconsistency of findings across outcome measures (Evidence Review G pp.137-165, 334-335). The recommendations on considering physical activity programmes for people with ME/CFS (1.11.17 - 1.11.20) therefore introduce confusion to the guideline as to which types of activity programme are acceptable and which are not. The recommendation not to offer any therapy based on physical activity or exercise as a treatment or cure for ME/CFS is thus weakened. Existing GET programmes that are nominally compliant (e.g. by allowing increase by flexible increments) will remain in place under the new guise of 'optional physical activity programmes', and continue to do harm to people with ME/CFS. It has been suggested by GET proponents that the poor objective outcomes and high drop out rates reported for ME/CFS specialist clinics, and the lack of support for GET from people with ME/CFS is due to an implementation problem. However, even under clinical trial conditions with delivery by well trained experts, there has been no objective evidence of benefit from any exercise or activity program. We are pleased to see the guidance not to offer any therapy based on physical activity or exercise as a treatment or cure for ME/CFS (p.28 lines 1-2) and some of the specific guidance not to offer certain types of physical activity or exercise programmes and therapies in 1.11.16. However, the section on 'Physical activity' does not go far enough to protect people with ME/CFS from harmful programmes. There is no justification for offering any sort of activity programme to people able to mobilise without aids. 'Programmes', however slow and gentle, are by their nature timetabled and structured, and often done in a group setting, which can encourage people to push through to keep up with the group.

				It is inappropriate to offer activity programmes to people if they 'would like' them as this offers a false version of patient choice, implying by the existence of such a programme that it will improve the person's health, or the NHS would not be offering it. People with ME/CFS long to be able to do more, and find it difficult to manage cutting back their activities sufficiently to avoid PEM. Any suggestion that an activity programme might be helpful if they 'would like' it, is not supported by evidence. We propose the content of the 'Physical activity' section be deleted and replaced with the following: *1. People with ME/CFS need advice and support to rest and avoid over-exerting to minimise PEM. If a person feels they are able to increase activity, they should be advised to proceed cautiously, particularly on good days when they may think they can do more without resulting PEM. If requested, referral to a specialist physiotherapist with up-to-date training in ME/CFS consistent with this guideline should be provided to those with problems mobilising without aids who need specialist advice.* *2. If able to increase, people with ME/CFS, particularly if already ambulant, will generally do this naturally without input from a* healthcare professional (*HCP).* *3. 'Activity' and 'physical activity' are defined in the guideline and HCPs should recognise that an increase of any type of activity, however seemingly trivial, may cause worsening for people with severe or very severe ME/CFS.* *4. Do not advise people with ME/CFS to undertake general exercise, such as going to the gym or exercising more, because this may worsen their symptoms.* *5. Therapy based on physical activity or exercise is not a treatment or cure for ME/CFS and should not be offered as such.* *6. There is no reliable evidence that physical activity programmes are effective in managing ME/CFS or its symptoms, or increasing function or tolerance to activity. They should not be offered as such.* *7. Offering activity programmes with the objective of managing ME/CFS or its symptoms, or increasing function or tolerance to activity, can be regarded as offering them to treat ME/CFS. Any therapy based on physical activity or exercise as a treatment or cure for ME/CFS should not be offered* (Rationale and impact, p.63 lines 7-8). *8. Do not offer the following to people with ME/CFS:* *a. generalised physical activity or exercise programmes. This includes programmes developed for healthy people or people with other illnesses;* *b. any programme that has increasing activity or exercise as its objective, regardless of whether this is by fixed or flexible increments, for example graded exercise therapy;* *c. any activity or exercise programme based on a hypothesis of the cause of ME/CFS, as this is not yet known. This includes activity or exercise programmes based on deconditioning, central sensitisation, or fear avoidance, and ones that aim to desensitise people with ME/CFS to exertion or triggers (eg., light, sound) through exposure.*

				d. therapies derived from osteopathy, life coaching and neurolinguistic programming (for example the Lightning Process). We are pleased that some of the above is addressed at 1.11.15 and 1.11.16. However, we do not feel the guideline adequately protects patients from harm in its current form.
164	Guideline	27	20	We provide comments on each recommendation in support of our suggestion to replace the current 'Physical activity' section as outlined above. These comments should also be considered as stand alone feedback.
165	Guideline	27	21-23	This clause needs clarifying. It is not clear if supervised unstructured or unsupervised structured exercise is acceptable and these terms are not defined. Suggested edit: '*Do not advise people with ME/CFS to undertake general exercise, such as telling them to go to the gym or to exercise more, as this may worsen their symptoms*.'
166	Guideline	28	1-2	Suggest replace with '*Any therapy based on physical activity or exercise as it is not a treatment or cure for ME/CFS and should not be offered as such.*' (Rationale and impact, p.63 lines 7-8).
167	Guideline	28	3-5	Good. Should be retained.
168	Guideline	28	6-7	Suggest replace with: '*any programme that has increasing activity or exercise as its objective, **regardless of whether this is by fixed or flexible increments,** for example graded exercise therapy.*' By specifying that programmes based on fixed incremental increases should not be offered, any programme based on flexible increases would remain acceptable under the guideline. E.g. Programmes with scheduled increases except when PEM is present may be viewed as incorporating flexible increments and therefore guideline compliant, yet may do significant harm. There is no standard definition of GET (Evidence Review G, p.335 lines 8-10), and therefore no requirement that increases in GET programmes must be by fixed increments. It can be seen from Evidence Review H that, in fact, studies of GET included in the evidence review did include flexible increments. It is therefore clear that the portrayal of programmes involving fixed increments as poorly evidenced and potentially harmful and programmes involving flexible increments as of potential benefit is a false distinction; studies of GET programmes have been assessed as low or very low quality evidence regardless of whether they involve fixed or flexible increments, with inconsistency of findings across outcome measures (Evidence Review G pp.137-165, 334-335). We provide excerpts from study summaries in Evidence Review H, illustrating increasing by non-fixed increments: Broadbent (2016), pp.34-35: *'Exercise sessions were progressed by increasing the duration of the session only as tolerated for each participant. The workload was not increased until participants had achieved three consecutive exercise sessions of 30 min in total with no increase in symptoms, and the increase was 10% of the current workload. If participants*

				reported any increase in fatigue or other symptoms during post-exercise, the exercise intensity was reduced until participants felt able to manage progression.' Clark (2017), pp.92-93: *'If symptoms increased after an incremental change in activity, participants were advised to maintain activity at the same level until symptoms had settled, before considering another incremental increase.'* Wallman (2004), pp.230-231: *'Subjects were instructed to exercise every second day unless they had a relapse. If this occurred or if symptoms became worse, the next exercise session was shortened or cancelled and subsequent sessions were reduced to a length that subjects felt was manageable (pacing)'* Descriptions of other GET study interventions included in the evidence review also indicated that increasing was not by fixed increment (Fulcher, 1997; Wearden, 1998; White, 2011). Further, Evidence Review G acknowledges the heterogeneity of interventions described in GET studies (p.335, lines 9-10). Therefore, it is not sufficient to recommend that 'any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy' should not be offered to people with ME/CFS. To accurately reflect the evidence and adequately protect people with ME/CFS from harms, lines 6-7 should recommend that all programmes that have increasing activity or exercise as their objective, regardless of whether this is by fixed or flexible increments, should not be offered to people with ME/CFS. This includes but is not limited to GET.
169	Guideline	28	8-9	Delete 'structured'. Suggested edit: '*any activity or exercise programme based on a hypothesis of the cause of ME/CFS, as this is not yet known. This includes activity or exercise programmes based on deconditioning, central sensitisation, or fear avoidance, and ones that aim to desensitise people with ME/CFS to exertion or triggers (eg., light, sound) through exposure.*'
170	Guideline	28	10-11	Good. Should be retained.
171	Guideline	28	1-11	Include an additional recommendation after 1.11.16: '*There is no reliable evidence that activity programmes are effective in managing ME/CFS or its symptoms or increasing function or tolerance to activity. Therefore they should not be offered as such.*'
172	Guideline	28	12-15	Should be deleted and replaced with: '*People with ME/CFS will typically naturally increase physical activity if there is an increase in capacity. Advise taking any increases in activity slowly and to cut back and rest more if symptoms increase. Refer to a specialist physiotherapist with up-to-date ME/CFS training consistent with this guideline if requested.*' Rationale: The recommendation for physical activity programmes in this section gives mixed messages about the acceptability of activity programmes and will lead to inappropriate programmes continuing in place with resultant

				harms to people with ME/CFS. The words '*incorporate physical activity into the management of their ME/CFS'* suggests such programmes may be used to manage ME/CFS. There is no reliable evidence for this. Evidence quality for all GET and other exercise intervention studies were judged to be of low or very low evidence quality, with inconsistency of findings across outcome measures (Evidence Review G pp.137-165, 334-335). If a condition is successfully managed by a programme, then it is treated by it; the guideline states that therapy based on physical activity should not be offered as a treatment for ME/CFS (1.11.16; Rationale and impact, p.63 lines 7-8). The words '*ready to progress their physical activity*' imply patients are failing in condition management in some sense if not able to increase activity. Use of the word 'or' in line 14 suggests that people who would like to do some more physical activity should be offered it, regardless of whether they are able to progress their activity beyond their current activities of daily living or not.
173	Guideline	28	16-18	If retained, should specify programmes offered should be consistent with this guideline. Physiotherapists and occupational therapists delivering such programmes should have up-to-date ME/CFS training consistent with this guideline.
174	Guideline	28	19-22	Self report is not sufficient basis for a recommendation, and is often contradicted in trials of adequate methodology (e.g. where sufficient blinding and/or objective outcome measures are employed). There is no reliable evidence of benefits of a physical activity programme, yet this recommendation claims benefit without specifying what it is. A therapy that leads to benefits must be regarded as a treatment; the guideline specifies therapy based on physical activity or exercise should not be offered as a treatment or cure for ME/CFS (1.11.16; Rationale and impact, p.63 lines 7-8). Many have reported long-term and significant worsening after an activity or exercise programme; this clause does not adequately convey risk. Statements like this should not be in an evidence-based guideline.
175	Guideline	28	23	Recommendation 1.11.20 describes a form of graded exercise therapy and has no place in the guideline. It illustrates why it is not possible to recommend activity programmes without inadvertently sanctioning harmful activity programmes. The guidance to start by reducing activity and to '*use flexible increments for people who want to focus on improving their physical activities while remaining within their energy envelope*' is not sufficient to distinguish this from harmful activity programmes for which there is no reliable evidence of effectiveness, including GET. There is no standard definition of GET (Evidence Review G, p.335 lines 8-10), and therefore no requirement that increases in GET programmes must be by fixed increments. It can be seen from Evidence Review H that, in fact,

				studies of GET included in the evidence review did include flexible increments (Broadbent, 2016; Clark, 2017; Fulcher, 1997; Wallman, 2004; Wearden, 1998; White, 2011). It is therefore evident that the portrayal of programmes involving fixed increments as poorly evidenced and potentially harmful and programmes involving flexible increments as potentially helpful is a false distinction; studies of GET programmes have been assessed as low or very low quality evidence regardless of whether they involve fixed or flexible increments, with inconsistency of findings across outcome measures (Evidence Review G pp.137-165, 334-335). Therefore, it is not sufficient to recommend that '*any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy*' should not be offered to people with ME/CFS. To accurately reflect the evidence and adequately protect people with ME/CFS from harms, physical activity programmes should not be recommended in this guideline, irrespective of whether they involve increasing by fixed or flexible increments. 1.11.20 is overly prescriptive and may result in unworkably regimented routines, with worsening of or no reduction in symptoms and reduced quality of life. It appears to use the concepts of a 'baseline' and 'energy envelope' interchangeably and creates the expectation that physical activity can be successfully increased in flexible increments.
176	Guideline	28	25-26	We do not support the concept of a 'baseline' in ME/CFS, as this inaccurately implies a level of activity that does not cause PEM from which the person with ME/CFS can increase. 'PEM threshold' may be a more appropriate term. But such concepts translate less well to real life; many people with ME/CFS have little option but to routinely exceed their limits due to personal circumstances and obligations, and many with ME/CFS have no spare capacity to increase without inducing PEM. See Evidence Review G, p.333 lines 20-21 where (in reference to GET programmes) it is stated qualitative evidence showed '*baseline levels were not experienced as sustainable*' by people with ME/CFS.
177	Guideline	29	1-2	Assumes that people with ME/CFS are not using all of their 'energy envelope' and so there is unused capacity that can be devoted to physical exercise. This is not true; people with ME/CFS struggle to restrict their activity to a safe level. Also assumes that 'energy envelope' capacity (capacity for activity without inducing Post Exertional Malaise (PEM)) will be increased once a physical activity programme is embarked on, otherwise it would not be possible to continue increasing whilst remaining inside the energy envelope. There is no reliable evidence that physical activity programmes lead to such an increase in capacity and no reason to think that such programmes will not lead to harms.
178	Guideline	29	6-7	'Agree with' should be replaced with 'Discuss with'. The current wording may lead to the person with ME/CFS having to negotiate adjustments to physical activity with a healthcare professional (HCP) and compromise if views on activity levels differ.

179	Guideline	29	8-13	We do not generally see the relevance of accessing specialist ME/CFS physiotherapy services during Post Exertional Malaise (PEM) or prolonged deterioration (relapse), when rest and reduction of activity should be prioritised. We suggest lines 8-13 be replaced with: '*reducing activity and increasing rest for as long as needed until symptoms improve, and being aware that after PEM or a longer deterioration, they may not be able to return to the previous level of activity. Access may be provided to a physiotherapist with up-to-date training consistent with this guideline for advice on physical maintenance if appropriate.'*
180	Guideline	29	12-13	We do not support the concept of a 'baseline' in ME/CFS, as this inaccurately implies a level of activity that does not cause Post Exertional Malaise (PEM) from which the person with ME/CFS can increase. 'PEM threshold' may be a more appropriate term. But such concepts translate less well to real life; many people with ME/CFS have little option but to routinely exceed their limits due to personal circumstances and obligations, and many with ME/CFS have no spare capacity to increase without inducing PEM. See Evidence Review G, p.333 lines 20-21 where (in reference to GET programmes) it is stated qualitative evidence showed '*baseline levels were not experienced as sustainable*' by people with ME/CFS.
181	Guideline	29	14-16	Add that they may need to adapt to a new lowered level of physical activity in the long-term.
182	Guideline	29	17	CBT should not be offered to support people to manage sleep issues in ME/CFS, as the evidence review found no reliable evidence of benefit of CBT for sleep quality, and quality of evidence for all outcomes across all CBT clinical studies included in the evidence review was found to be low or very low (Evidence Review G, p.323-324, 72-119).
183	Guideline	29	19	We are pleased to see that rest is recognised as key in managing ME/CFS. Add 'important', i.e., '*on the **important** role of rest in ME/CFS*'.
184	Guideline	29	21-22	It is not appropriate for healthcare professionals (HCPs) to advise people with ME/CFS 'how often and for how long' rest periods should be. This should be determined on an ongoing basis by the person with ME/CFS. delete: '*including how often and for how long, as appropriate for each person*'
185	Guideline	29	18-22	Add a bullet point to 1.11.23: '*Where hypersomnia is present, do not restrict sleep*.' There is no reliable evidence that sleep restriction leads to a reduction of ME/CFS symptoms, and some patients and their carers report that it can cause harm. Unrefreshing sleep is one of the required symptoms for suspecting ME/CFS (p.8, Box 1). It is not something that can be resolved by standard sleep hygiene recommendations.
186	Guideline	29	18-22	Add a bullet point to 1.11.23: '*Sleep during the day may be helpful; the person with ME/CFS should find what works best for them*'.
187	Guideline	29	18-22	Add an additional bullet point to 1.11.23: '*that people with severe or very severe ME/CFS may need to spend extended periods or all of their time lying in a dark, completely quiet room with little or no stimulation in order to avoid worsening*.'
188	Guideline	30	1-2	Delete. This recommendation could be used to promote 'techniques' that have no more evidence to support them as being beneficial for rest or for ME/CFS symptoms than common sense approaches to achieving rest.

189	Guideline	30	2	Add a recommendation after 1.11.23 clarifying guidance for GPs on prescribing medication to help with sleep if a person with ME/CFS needs it.
190	Guideline	30	6	add: '*or hypertension*' after hypotension, as some people experience orthostatic hypertension and treatment for this is different.
191	Guideline	30	6	After 1.11.24 insert a recommendation: '*Be aware that* in *those with severe and very severe ME*/CFS, *orthostatic intolerance may be very severe, and result in the person not being able to sit up for more than a few seconds or minutes, or at all.'*
192	Guideline	30	7-12	After 1.11.26, add a recommendation: '*Any clinician treating a person with ME/CFS for orthostatic intolerance should have up-to-date ME/CFS training consistent with this guideline and therefore understand that exercise may worsen the symptoms of ME/CFS, including orthostatic intolerance.'*
193	Guideline	30	13-16	Include that CBT should not be offered to support people to manage pain in ME/CFS, as there is no reliable evidence this leads to improvement. The evidence review showed no finding of benefit (versus usual care) and inconsistency of findings (versus other interventions) for pain outcomes, and quality of evidence for all outcomes across all CBT clinical studies included in the evidence review was found to be low or very low (Evidence Review G, pp. 72-119, 323-324).
194	Guideline	30	13-16	Recommendation 1.11.27 should include more guidance on treating pain in ME/CFS, including '*pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion'.* These types of pain are described as symptoms that may be associated with ME/CFS at 1.2.4 (p.9, lines 15-16) of this draft guideline.
195	Guideline	30	13-16	Add: '*Some people with ME/CFS find that over the counter pain medication may reduce their pain levels. Due to restricted mobility and access to shops, over the counter pain medication should be available by repeat prescription in packs larger than those available without prescription, subject to regular review and clear advice on dosing, side effects and risks of long-term use.'*
196	Guideline	30	13-16	Many people with ME/CFS have chronic pain and are often unable to engage in activities that could distract from the pain. This makes pain relief particularly important. Opioid pain relief is important for quality of life for some people with ME/CFS; access to this needs to be protected unless satisfactory alternatives can be provided. The NICE guideline on neuropathic pain in adults only refers to Tramadol in rare acute cases.
197	Guideline	30	13-16	Add: '*New or worsening pain symptoms should be appropriately investigated and not assumed to be caused by ME/CFS.*'
198	Guideline	30	13-16	Include that if pain has been appropriately investigated, and cannot be managed in primary care, it is possible that people with ME/CFS will be referred on to a pain management clinic. It is essential that all clinicians involved have up-to-date ME/CFS training in accordance with this guideline. Some approaches to pain management, particularly those involving exercise programmes for management of pain, can be harmful to people with ME/CFS.

199	Guideline	30	13-16	We note the recent confirmation by Dr Paul Chrisp of NICE that the draft NICE guideline on chronic pain does not and will not apply to people with ME/CFS. https://meassociation.org.uk/2020/0...-get-covid-19-and-new-guideline-chronic-pain/. This is important as the chronic pain guideline, with its focus on exercise, psychological therapies and alternative medicine, and withdrawal of pain relief drugs, is completely inappropriate for people with ME/CFS. Add: '*the NICE guideline on chronic pain does not apply to people with ME/CFS*.'
200	Guideline	31	1-4	Add: '*Prescribe medication for nausea if needed*.'
201	Guideline	31	1-4	Add: '*New or worsening nausea symptoms should be investigated, rather than assumed to be part of ME/CFS*.'
202	Guideline	31	14	add an additional bullet point regarding approaches to drug treatment of symptoms: • '*trialling different drugs one at a time*'
203	Guideline	32	7	After 1.11.34, add: '*Some people with ME/CFS, particularly with severe or very severe presentation, can develop difficulty eating due to gastrointestinal issues. They should be offered referral to a gastroenterologist and appropriate investigations and care.* *'Healthcare professionals and others should not confuse a difficulty eating due to ME/CFS-related gastrointestinal complications with psychologically based eating disorders. People with ME/CFS with difficulty eating should be treated with dignity and respect in accordance with this guideline, particularly the section 1.8 Access to Care.'*
204	Guideline	34	1	**Comment on the subsection 'Psychological support: cognitive behavioural therapy'** We recommend the subsection 'Psychological support: cognitive behavioural therapy' (1.11.43 - 1.11.50, pp.34-35) be deleted in its entirety from the section 1.11 'Managing ME/CFS'. A shorter subsection on psychological support should be created in the section 1.6 'Information and support' after the parts headed 'Communication' and 'Information about ME/CFS'. This new subsection should include basic general information on psychological support, and clear statements that CBT should not be offered to treat, cure or support people to manage their ME/CFS or the symptoms of ME/CFS, as detailed below. Rationale for deletion of this section in its current form: 1. There is no reliable evidence for the effectiveness of CBT to treat, cure, or improve the functioning of people with ME/CFS, or to support them to manage ME/CFS symptoms. The section makes repeated inappropriate reference to CBT to support people to manage ME/CFS symptoms and improve functioning. Quality of effectiveness evidence for all outcomes across all CBT studies included in the evidence review was found to be low or very low. This includes outcomes for physical functioning, quality of life, general symptom scales, and

				activity levels; and comparisons of CBT with usual treatment and other interventions (Evidence Review G, pp.72-119, p. 318 line 23). 2. Reference in this section to supporting people to manage ME/CFS symptoms and ‘improve functioning’ conflates psychological support, with which the section purports to concern itself, with CBT to treat ME/CFS. This will lead to confusion resulting in CBT being offered to treat ME/CFS, therapists exceeding their expertise and resultant harm to people with ME/CFS. In discussing why benefits to quality of life and psychological status were not demonstrated in the clinical effectiveness evidence the Committee suggested there may be ‘summative benefits’ across other study outcomes including physical function, fatigue and activity levels, that ‘may lead to longer term improvements in quality of life and psychological distress’ (Evidence Review G, p.326). There is no reliable evidence for such 'summative benefits'. Assumptions based on qualitative evidence (which should be interpreted with caution) are not an adequate basis for including recommendations that CBT may be offered to support people to manage symptoms of ME/CFS or improve function or quality of life. (Evidence Review G p.320 also points to the quality of the qualitative studies being moderate to very low.) 3. There is no evidential basis for referring solely to CBT to the exclusion of other forms of psychological support. Our members have expressed preference for general psychological support, which may be provided informally by a healthcare professional (HCP) in conjunction with medical care. However, we suggest that information on psychological support should be generic and not mention specific modes or therapies. 4. Qualitative evidence suggesting benefits of CBT (see Evidence Review G p.324) should be interpreted with caution. Our forum members report telling a therapist they feel better due to wanting to please them and wanting to feel hopeful, when in fact nothing had changed. Of the members of the ME Association (https://meassociation.org.uk/managing-my-me-me-association-publish-results-of-huge-survey-report/) responding to a survey on helpful therapies for ME/CFS in 2010, 50% felt that counselling could be useful whereas only 28% reported that CBT could be useful. 5. We propose a consultant-led approach to management of ME/CFS, in which support with energy management would be provided by a specialist nurse who would also assist with symptom monitoring and management. CBT therapists are not qualified to provide these aspects of care; to do so would exceed their expertise and risk harm to people with ME/CFS. Rationale for movement of the 'Psychological support' out of 1.11 'Managing ME/CFS':

				Coverage of psychological support should not be included in section 1.11 'Managing ME/CFS' because there is no reliable evidence that CBT can effectively support people to manage ME/CFS or its symptoms. Instead, brief coverage of psychological support should be included in section 1.6 'Information and support'. The proposed subsection on psychological support in 1.6 'Information and support' should explain that: 1. Practical care, such as ensuring family and carers understand the illness, assisting with discussions with an employer, helping the person gain financial assistance and putting them in touch with peer group support, is important in helping the person cope. Our members report that this reduces the likelihood that formal psychological support will be needed. 2. Informal support is an important part of routine healthcare interactions, and should be considered a relevant aspect of care by all healthcare workers. Medical health care professionals are often well placed to provide informal psychological support as they may have an existing relationship with the person with ME/CFS and their family that pre-dates illness onset and they may have a good understanding of the health issues the person faces. 3. CBT and other psychological therapies are not a treatment or cure for ME/CFS, or for the symptoms of ME/CFS, and should not be offered as such (1.11.43 p.34; Rationale and impact p.67). 4. There is no reliable evidence that CBT or other psychological therapies are effective for improving function in people with ME/CFS, or in supporting them to manage ME/CFS or its symptoms. All CBT clinical studies were judged to be of low or very low evidence quality, and for all outcomes there were either no findings of benefit (e.g., quality of life) or inconsistency of findings (e.g., physical function, general symptom scales, fatigue, pain). (Evidence Review G pp. 72-119, 323-324). 5. Psychological support should be arranged if requested by the person with ME/CFS. It may also include information on psychological support for people with ME/CFS together with their partners or family members to help them to collectively adapt to changes brought about by the illness. 6. If a person with ME/CFS develops a mental health condition, NICE guidance for that condition should be followed. Grief, sadness, frustration and anger are normal reactions to the losses caused by ME/CFS; care should be taken to distinguish these from mental health conditions. HCPs providing psychological support for comorbid mental health conditions should have up-to-date ME/CFS training in accordance with this guideline to ensure that proposed treatment approaches to such conditions take the post-exertional malaise and other limitations particular to ME/CFS adequately into account in order to avoid harms.

				7. Those providing supportive psychological therapies should have experience of ME/CFS and have training in accordance with this guideline. They should understand the constraints imposed by ME/CFS, and that the cause of ME/CFS is not understood, but there is no evidence that it is caused or perpetuated by deconditioning or faulty thoughts or behaviours. We provide comments on each recommendation in support of our suggestion to delete the subsection 'Psychological support' and include a shorter subsection on psychological support in 1.6 'Information and support'. These comments should also be considered as standalone feedback.
205	Guideline	34	2-5	The guidance not to offer CBT as a treatment or cure for ME/CFS is welcomed, but should be clearer. Suggested wording: '*CBT and other psychological therapies are not a treatment or cure for ME/CFS, or for the symptoms of ME/CFS, and should not be offered as such.*' The rest of this paragraph should be deleted. There is no reliable evidence that CBT is effective for supporting people to manage symptoms of ME/CFS. Quality of evidence for all outcomes across all CBT clinical studies included in the evidence review was found to be low or very low. This includes outcomes for physical functioning, quality of life, general symptom scales, and activity levels (Evidence Review G, pp.72-119).
206	Guideline	34	5	After 1.11.43 add a recommendation: *'The risks of undergoing a course of CBT should be explained to people with ME/CFS of all severity levels, including that the physical cost of the interaction required to engage in the process may outweigh any perceived benefits. The cognitive and physical exertion involved may cause deterioration even for people with mild ME/CFS.'*
207	Guideline	34	4	The term 'distress' should not be used. This assumes psychological distress that may not be present. Finding chronic illness difficult is a normal response to the debility and unwellness it entails, but 'distress' suggests more than this. Use of the term 'distress' throughout the draft guideline is further discouraged due to existence of the concept 'Bodily distress disorder' (ICD-11) which may inappropriately capture a subset of ME/CFS patients. The guideline should not use terminology that creates overlap with unrelated disorders focused on distress at bodily symptoms.
208	Guideline	34	6-8	Should include recommendation to not refer people with ME/CFS to Improving Access to Psychological Therapies (IAPT) services, as IAPT therapists do not have appropriate training and experience in working with people with ME/CFS. (See Evidence Review G, p.326 lines 25-31.)
209	Guideline	34	6-8	Add that training and experience should be up-to-date and consistent with this guideline.
210	Guideline	34	10	The words *'manage the impact of [symptoms]'* should be deleted. There is no reliable evidence CBT is effective for this and the draft guideline acknowledges CBT is not a treatment or cure for ME/CFS (1.11.43, p.34; Rationale and impact, p.67). Quality of evidence for all outcomes across all CBT clinical studies included in the evidence

				review was found to be low or very low. This includes outcomes for physical functioning, quality of life, general symptom scales, and activity levels (Evidence Review G, pp.72-119).
211	Guideline	34	14	The words '*aims to improve functioning*' should be deleted. There is no reliable evidence that CBT can improve functioning in ME/CFS. Only treatments of ME/CFS or its symptoms would improve functioning. The draft guideline acknowledges CBT should not be offered as a treatment or cure for ME/CFS (1.11.43, p.34; Rationale and impact, p.67). Further, this clause is likely to encourage therapists to operate outside the bounds of their expertise, risking harm to people with ME/CFS. Quality of effectiveness evidence for all outcomes across all CBT studies included in the evidence review was found to be low or very low. This includes outcomes for physical functioning, quality of life, general symptom scales, and activity levels (Evidence Review G, pp.72-119).
212	Guideline	34	14	The term 'distress' should not be used. This assumes psychological distress that may not be present. Finding chronic illness difficult is a normal response to the debility and unwellness it entails, but 'distress' suggests more than this. Use of the term 'distress' throughout the draft guideline is further discouraged due to existence of the concept 'Bodily distress disorder' (ICD-11) which may inappropriately capture a subset of ME/CFS patients. The guideline should not use terminology that creates overlap with unrelated disorders focused on distress at bodily symptoms.
213	Guideline	34	16-17	Should also include that 'abnormal' illness beliefs and behaviours do not perpetuate ME/CFS. Suggested wording: *'does not assume that ME/CFS is caused or perpetuated by 'abnormal' illness beliefs or behaviours*'
214	Guideline	34	16-18	The words '*recognises that thoughts, feelings, behaviours and physiology interact with each other*' should be deleted. This implies that the pathophysiology of ME/CFS can be altered by altering thoughts, feelings and behaviours, so symptoms can be altered using CBT. There is no reliable evidence for this. It is also virtually indistinguishable from the idea that abnormal illness beliefs or behaviours cause (or perpetuate) ME/CFS, which the draft states CBT for people with ME/CFS '*does not assume*'.
215	Guideline	34	21-29	Section 1.11.46 should be deleted. Too much information on CBT is provided here and in section 1.11 overall. There is no reliable evidence that CBT can treat or cure ME/CFS, or that it is effective for improving function in people with ME/CFS or supporting them to manage ME/CFS symptoms (evidence was rated low or very low quality for all CBT clinical studies, Evidence Review G, pp 72-119). Therefore, the extent of information provided on CBT is inappropriate. If it is offered as a supportive psychological therapy, it should be given no greater status than other psychological therapies.
216	Guideline	34	25-27	This bullet point should be deleted. Language like '*establish strategies*' and '*work towards meaningful goals and priorities*' can be interpreted to mean that increasing activity will be feasible if strategies are put in place. This is not psychological support CBT, but CBT that aims to treat.
217	Guideline	34	30	Recommendation 1.11.47 should be deleted. Too much information on CBT is provided here and in section 1.11 overall. There is no reliable evidence that CBT can treat or cure ME/CFS, or that it is effective for improving function in people with ME/CFS or supporting them to manage symptoms (evidence was rated low or very low

				quality for all CBT clinical studies, Evidence Review G, pp 72-119). Therefore the extent of information provided on CBT is inappropriate. If it is offered as a supportive psychological therapy, it should be given no greater status than other psychological therapies.
218	Guideline	34	30	The wording 'CBT for ME/CFS' suggests there is a particular kind of CBT that is effective and suitable for people with ME/CFS. There is no reliable evidence for this (evidence was rated low or very low quality for all CBT clinical studies, Evidence Review G, pp 72-119). It is important therapists working with people with ME/CFS have up-to-date ME/CFS training consistent with this guideline, but psychological support for people with ME/CFS (as for any chronic illness) does not require a special kind of CBT.
219	Guideline	35	3-4	This bullet point should be deleted. This can be interpreted to invite therapists to encourage people with ME/CFS to invent and impose personal meanings on their symptoms and illness, increasing the likelihood unevidenced hypotheses on causes of ME/CFS may be applied. It creates scope for ill-informed therapists causing people with ME/CFS to feel blamed for their illness (See Evidence Review G, p.327, lines 8-15 on the importance of validation and non-blaming attitudes). There is no reliable evidence that such an approach is helpful and we think it poses a risk of harm to people with ME/CFS. Also, see Evidence Review G (p.325 lines 33-38) where noted experiences of CBT included perceptions of CBT as ‘controlling, patronising and a form of brainwashing’.
220	Guideline	35	5-7	What examples of self-management strategies are envisaged to be appropriate in a course of CBT for a person with ME/CFS? These lines should be deleted. There is no reliable evidence that CBT helps with people with ME/CFS's functioning and quality of life, including their sleep, activity or rest. Quality of evidence for all outcomes across all CBT clinical studies included in the evidence review was found to be low or very low. This includes outcomes for physical functioning, quality of life, general symptom scales, and activity levels. For all outcomes there were either no findings of benefit (e.g. quality of life) or inconsistency of findings (e.g. including physical function, general symptom scales, fatigue, pain, quality of life). (Evidence Review G pp. 72-119, 323-324). Attempting to change functioning and activity is attempting to treat ME/CFS. The draft guideline specifies that CBT should not be offered as a treatment for ME/CFS (1.11.43, p.34; Rationale and impact, p.67). Further, this may encourage CBT therapists to operate outside their expertise, risking harm to people with ME/CFS. Unrefreshing sleep is required for suspicion of ME/CFS in this guideline (p.8, Box 1). It is not a 'secondary disability' or 'psychological effect' of ME/CFS as suggested in Evidence Review G (p.326 lines 18-22). Therefore, it is not appropriate to offer CBT to support people to manage sleep symptoms of ME/CFS, and there is no reliable evidence that this will lead to improvement for any outcome measure.
221	Guideline	35	8	This line should be deleted. It does not make sense to have a 'self-management plan' separate from a 'management plan'. The person's management plan needs to include medical symptom management as well as energy management, as each may impact the other. This requires the training of a doctor or specialist nurse. A CBT therapist is not qualified to assist the patient with the management of physical symptoms and medication.

222	Guideline	35	9-11	These lines should be deleted. It does not make sense to have a 'self-management plan' separate from a 'management plan'. CBT therapists lack the appropriate expertise to review management plans for ME/CFS which need to include medical management of physical symptoms alongside energy management. The ME Association reported in 2010, based on a survey of their members, that a psychologist or psychiatrist was the least preferred health professional to co-ordinate the management of a person's ME/CFS illness. 'Managing my ME' report | The ME Association (https://meassociation.org.uk/managing-my-me-me-association-publish-results-of-huge-survey-report/)
223	Guideline	35	12-13	We question the need for a 'therapy blueprint' separate from the patient's management plan (medical care plan) and suggest this CBT tool has no place in the guideline for ME/CFS, as there is no evidence that dysfunctional beliefs have any role in causing or perpetuating ME/CFS.
224	Guideline	35	15-17	If this paragraph is included in the guideline, the risks of CBT should be described. It should include recommendation to ensure that the child or young person does wish to have CBT as supportive psychological therapy, and is not simply appeasing a parent or healthcare professional. The draft guideline includes the acknowledgment that children may have experienced prejudice and disbelief about their illness (draft guideline 1.1.6, p.5). Young people with ME/CFS have been harmed by CBT. Therapists should not contradict the child or young person's experience of ME/CFS, as views of the therapist are likely to be given more weight than the child's views. Therapists should not speculate about the cause of ME/CFS or pressure the child to increase any form of activity.
225	Guideline	35	23-26	Evidence Review G (p.328 lines 38-39), states, '*The committee noted that none of the evidence [on CBT] included or reflected the needs of people with severe or very severe ME/CFS.*' Therefore the guideline should recommend that people with severe or very severe ME/CFS should not be offered supportive CBT for ME/CFS, and particularly not CBT that is geared '*to support them in managing their symptoms of ME/CFS*', or to improve function, as there is no evidence of benefit but significant risk of harms.
226	Guideline	35	23-26	Include that ***all people*** with ME/CFS are likely to struggle with the cognitive and physical effort of psychological support sessions and will benefit from shorter, less frequent sessions and longer-term goals. People severely affected by ME/CFS are likely to struggle greatly with the physical and cognitive effort, or be completely unable to undertake it. Strategies such as communication by email may help. Add: *'Risk assess any proposed course of CBT or other formal psychological support for a person with severe or very severe ME/CFS in advance to ensure that perceived benefits outweigh the risks to the person (for example, worsening their symptoms).'*
227	Guideline	36	5-6	This is an important point and needs emphasising. We suggest adding: Note that doctors need to be alert to the development of new comorbidities, and not assume new symptoms are part of ME/CFS even if they overlap with ME/CFS symptom lists.

228	Guideline	36	5-6	Add: Be aware that people with ME/CFS may be more sensitive to drugs, and may need to start with smaller doses where possible, and some drugs may worsen ME/CFS symptoms. Be aware that treatments for coexisting conditions that include exercises may be contraindicated for people with ME/CFS.
229	Guideline	36	7-11	Add links to guidelines for postural orthostatic tachycardia syndrome (PoTS), Irritable bowel syndrome (IBS), gastroparesis, migraine and any other common comorbidities that have NICE guidelines.
230	Guideline	36	12	Add: Care needs to be taken in diagnosing depression on the basis of questions about, for example, fatigue and lack of participation in social activities which may be caused by the patient's ME/CFS not by depression.
231	Guideline	36	12	Add: Care needs to be taken to avoid misdiagnosing the natural healthy reactions of sadness and anxiety that occur when diagnosed with ME/CFS as mental health conditions. Acknowledgement of the severity of symptoms and practical support are likely in most cases to be more appropriate than a mental health referral.
232	Guideline	36	12	Add: If a comorbid mental health condition is diagnosed and the patient agrees to treatment, ensure that the provision of treatment and ongoing care is adapted to the limitations and needs of a person with ME/CFS, and provided by a professional with up to date knowledge of ME/CFS in accordance with this guideline.
233	Guideline	37	1	**Comment on section 1.13 Managing flares and relapses** We find that the whole guideline, especially the management sections, focuses almost entirely on day-to-day management, and offers little, if any, information or guidance for clinicians or patients on dealing with the major life changes that most patients face. Apart from the sections specifically about severe and very severe ME/CFS, there is little recognition that those with moderate ME/CFS, which may be the majority of patients, face complete upheaval of their work, education and personal lives, as many are completely or virtually housebound, have difficulty accessing services, medical care and financial support. The impression is of minor adjustments, with family support available. That is not true for a large proportion of patients. Some of the sections for severe ME/CFS patients apply to those with moderate ME/CFS as well.
234	Guideline	37	1	We suggest section 1.13 on managing flares and relapses should be part of, or come immediately after, the section on energy management, since it is an integral part of energy management with the same strategies of staying within the person's sustainable activity level, and making sure the person gets sufficient rest, according to their symptoms. Advice about energy management needs to include advice on how to manage any downturn, using symptom contingent pacing, whether it is a fluctuation, flare, PEM, PESE, relapse or prolonged deterioration. It is important that this topic be covered, as many new patients and doctors won't know what to do when symptoms worsen, but it is part of energy management, not really a separate issue.
235	Guideline	37	2	Change the section title from '*Managing flares and relapses*' to '*Managing post-exertional malaise and prolonged deterioration*' The term flare is not one in common use, and in this context avoiding any mention of PEM seems perverse, since it is the most widely used term in diagnostic criteria, research papers and materials produced by patient

				organisations. Omitting it is likely to cause confusion. (we have suggested elsewhere that the terms flare and PESE should not be used in the guideline). We also suggest that 'relapse' may be misleading, as it is usually used in other conditions to refer to a recurrence of illness after a period of remission. In the case of ME/CFS, 'prolonged deterioration' may be a better way to describe what happens.
236	Guideline	37	9	Add: '*Complete bed rest may be necessary during episodes of PEM*' This is important, as many clinicians and family members don't understand just how sick people with ME/CFS can be with PEM.
237	Guideline	37	12-13	Add an extra point: '*Ensure this advice is discussed with patients in advance and included in their management plan (medical care plan), including who to contact for support and arranging extra care if needed.'*
238	Guideline	38	1	This makes it sound as though the patient needs to wait for agreement from a clinician before cutting back on activity during a relapse, which is unrealistic and inappropriate. Patients experiencing a prolonged deterioration (relapse) need to know in advance how to respond and who to contact for support if necessary. Suggested wording: '*During a period of deterioration, support the person in following the advice in their medical care plan*'
239	Guideline	38	3	Delete 'even'. Patients whose condition deteriorates will need to cut back significantly on activities. This section is in danger of suggesting that only minor adjustments will be needed, when the reality for some is a step down to a significantly more severe level of ME/CFS.
240	Guideline	38	5	The wording here is unhelpfully vague and misleading. The use of a metaphor 'energy envelope' here is liable to lead to misunderstanding and overcomplicates the issue. It makes it sound as though the person has control over their 'energy envelope' and can manipulate it in order to stabilise symptoms. It also implies that some sort of planning or scheduling is possible. Realistically all the person can do is try to rest sufficiently to avoid further worsening. Suggested alternative wording: 'Recognise that the person will need to rest a lot more and ensure they have the support to enable them to do so. Advise them not to attempt to increase activity until symptoms improve sufficiently that the added activity does not lead to a worsening of symptoms.' We have proposed that the metaphor 'energy envelope' shouldn't be used, and plain language is preferred. The term 'symptom-contingent pacing' conveys in plain language that activity levels should be judged on current symptoms and the likely impact of activity on these, with the object of avoiding, and preventing further worsening during PEM and prolonged deterioration. This term can be clearly contrasted with potentially harmful forms of pacing, such as schedule-contingent or activity-contingent pacing.

				We are concerned that there is too much focus on working out envelopes and finding and recording new envelopes rather than on the key approach to preventing PEM and periods of deterioration, which is to rest as much as you need. If medical staff have any role during periods when symptoms have worsened, it is to be available in an accessible way to help with symptom relief if asked for, fit notes for employers, assist with getting care needs met, and reminding the patient to rest as much as they need to until they feel well enough to do more. There is an important role in helping the patient to give themselves permission to rest more than they feel they 'ought' to. Suggested additional point: "Ensure that the person with ME/CFS has, during PEM and periods of deterioration, • access to medical care for symptom relief, • if needed, fit notes and support for not returning to work or education until they can sustain the activity without causing worsening • if needed, additional assistance at home"
241	Guideline	38	1-5	Add an extra bullet point: 'Explain to and recognise that for people with ME/CFS, particularly while experiencing PEM, and all the time for those who are severe or very severe, sensory stimuli (including sound, light and smells) and other environmental factors (e.g. temperature) can cause and worsen PEM and/or deterioration. Exposure need not be substantial or prolonged to cause significant worsening.'
242	Guideline	38	9	Add: If PEM does not start to resolve within the usual time for that person, or new symptoms appear, investigate other possible causes for worsening symptoms which may be mistaken for an ME/CFS downturn.
243	Guideline	38	10-21	This implies that the person should discuss every worsening of symptoms with their clinician. This is unrealistic and, in many cases, unnecessary if the person is experienced in dealing with their fluctuations and PEM. Suggest adding starting the sentence with, 'If the person requests it, once an episode of PEM or deterioration...'
244	Guideline	38	10-21	The phrase 'resolved or stabilised', and the rest of this section do not give sufficient emphasis to the fact that for many patients a period of deterioration leads to a very prolonged downturn to a greater severity level. It is important to emphasise that just advising making another 'Management Plan' (Medical Care Plan) on its own is insufficient. The logistics need to be organised in advance by the health provider for making a management plan (medical care plan) with a person who is too sick to attend a clinic, and may be too sick to cope with a home visit, and the talking involved, without further deterioration. Health providers need to ensure that services are available to ensure the management plan (medical care plan) can be implemented in a way that the person's health can tolerate, and is acceptable to the person. Flexible arrangements need to be in place, which the person knows in

				advance, with details of who to contact and how they can get help to cope with all aspects of their new situation, and to get the ongoing medical and home care they need in an accessible way. We feel it is important to spell this out in this section. The transition from mild or moderate to severe or very severe ME/CFS is likely to necessitate significant input from medical and care services, and these need to take into account the effects of any interaction on a patient with sometimes extreme sensory sensitivities, severe symptoms, and the serious effects of prolonged bed rest. The health and care professionals involved in making the new management plan (medical care plan) and assisting the person in implementing it need to have up to date knowledge of severe and very severe ME/CFS in line with this guideline.
245	Guideline	39	2-4	This assumes the patient has a management plan. There is also a need to more clearly differentiate what care is appropriate in primary care and what requires specialist care. Replace the 'General' section with subheading '**Review of adults in primary care**'. Replace 1.14.1 and 1.14.2 with 'Offer adults with ME/CFS: • a review of their care and management plan (if they have one) at least once a year • more frequent reviews as needed, depending on the severity and complexity of their symptoms and the effectiveness of any symptom management.
246	Guideline	39	10	typo ME/CF should be ME/CFS
247	Guideline	39	16	'activity management strategies' should be 'energy management strategies' to be consistent.
248	Guideline	39	18	Emotional and social well being should only be included if the patient wishes. It should not be assumed that all patients wish to discuss these.
249	Guideline	39	21	Add a new subheading **'Review of adults in specialist care'** Add: People should be offered a review by ME/CFS specialist care if: • there are any new or deteriorating aspects of their ME/CFS condition that cannot or have not been satisfactorily managed in primary care • they do not have a management plan and would like one • their ME/CFS severity is severe or very severe (in which case reviews more often than once a year are appropriate) Add: 'Where possible, people should have a named contact for ongoing specialist care, even if they do not currently require such care.'
250	Guideline	39	23-25	This needs to be made firmer. As with any other patient, if the GP is concerned about a symptom and doesn't have expertise to deal with it, they should refer to the appropriate specialist, and not just to the ME/CFS clinic,

				which is unlikely to have the appropriate expertise either. Replace with '*Do not allow the presence of an ME/CFS diagnosis to delay specialist assessment of signs and symptoms. Refer the person to an appropriate specialist to ensure prompt evaluation. Ensure any specialist involved in the care of the person has an up to date understanding of ME/CFS management in accordance with this guideline.*'
251	Guideline	40	7-8	Since most paediatricians are unlikely to have up to date training in ME/CFS, and some who claim expertise currently promote GET or similar, we think it is important that this point emphasise that the GP needs to check whether the paediatrician has up to date knowledge of management of ME/CFS in line with this guideline. Add: 'Ensure any person involved in the care of the child or young person has an up to date understanding of ME/CFS management in accordance with this guideline before referring'.
252	Guideline	40	11	**Comment on section 1.15 Training for health and social care professionals** This new guideline presents a paradigm shift in the understanding of ME/CFS. It is essential that the recommendations are communicated urgently to clinical commissioning groups, specialist clinics, medical colleges and professional organisations of health and social care professionals, to prevent further harm.
253	Guideline	40	11	**Question 3 (From this form)** **What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** A National NHS initiative to update all Clinical Commissioning Groups (CCGs) about the new approach is needed. National training courses for all staff deployed to implement the new model of care should be provided both online and in person, and new information materials written for clinicians and patients. The leading professional bodies - the Royal Colleges, need to be brought on board with this, with their current outdated training modules removed and replaced by guideline compliant materials. We suggest the education group of the UK CFS/ME Research Collaborative (CMRC) should play a lead role in providing such materials, and should be provided with government funding to produce accredited training courses designed for consultants, GP's, specialist nurses, medical students and other allied health professions. It should not be left to local CCG's to produce their own training and materials, as most will not have appropriate staff with up to date knowledge, and there is a real danger that they will resort to assuming current providers of ME/CFS services will be willing or able to change their practices. It would also reduce the cost of unnecessary duplication of effort.

				Once a few new services are set up and approved by the leading education groups listed above, they can be used as models of good practice. We recommend the Telehealth service provided by the Australian ME/CFS charity Emerge. Their Telehealth nurses may be able to offer advice and even training online to NHS counterparts.
254	Guideline	40	12-15	ME/CFS is a relatively common serious long-term illness and yet health and care professionals typically currently graduate with little accurate knowledge of it. Add: 'ME/CFS should be covered in the undergraduate medical curriculum, and postgraduate physician, paediatric and general practice curriculums. It must also be included in training for allied health professionals, nurses and others involved with health and social care.'
255	Guideline	40	17-23	Replace first bullet point with: • provide evidence-based content and training methods compliant with this guideline (with input from people with ME/CFS) • Studies assessed as low quality or very low quality in this guideline should not be used to support training content. • Studies that suffer from the methodological limitations set out in p.317 of Evidence Review G should not be used to support training content We do not think the phrase 'developed and supported by specialist services' is appropriate. This is because there are differences of opinions among care providers on what the evidence shows, and therefore there is a need to unequivocally state that training materials must be compatible with the guideline's recommendations. Many current service providers base their practice and understanding of ME/CFS on the CBT/GET model and its underpinning theories, and many still openly state their allegiance to that model. There are other groups with knowledge of ME/CFS that are better placed to develop and provide training than most current service providers. We are pleased that NICE have acknowledged the fundamental importance of patient involvement in the understanding of this disease and development of new training programmes. Ensuring training materials, including existing training materials, are compliant with the guideline and then delivering the training will be a major task. It must be adequately resourced and undertaken by those who approach ME/CFS in accordance with current evidence. The UK CFS/ME Research Collaborative (CMRC) education group is trusted by our members, is already producing training aligned with this guideline, and has good connections with experts in particular

				aspects of ME/CFS management. Add: • have been approved by the CMRC education group • are compliant with this guideline; existing training programmes that are not compliant should be withdrawn and reviewed, and only offered again when compliant with this guideline
256	Guideline	41	4	Add: 'These should include all professionals whose role impacts on people with ME/CFS, including clinical commissioners, employers, schools, housing providers, benefits assessors, safeguarding, clinical and care staff, clinical professional bodies and staff involved in assessing Long COVID patients.' This will need to be expedited as soon as possible alongside the production of the new guideline.
257	Guideline	41	4	Add: 'All services caring for people with ME/CFS need to be assessed for compliance with the new guideline's training requirements. This needs to be carried out independently, rather than as a service evaluation.'
258	Guideline	41	5	**Comment on section 'Terms used in this guideline'** Explanation of terms used: The section 'Terms used in this guideline' states: 'Terms have been used in a particular way for this guideline'. We are concerned that new terms and new uses of terms will lead to misinterpretation when quoted and read out of context, or without reference to the definitions. We therefore think it vital that each term be defined in context, both at its first and any subsequent substantial use in the guideline. Hyperlinking is not sufficient.
259	Guideline	41	5	**Comment on section 'Terms used in this guideline'** Invention, redefinition and dropping of terms used: We question the appropriateness of NICE introducing or redefining terms. We think it more helpful, and evidence based, for current terms to be used, and defined according to common current usage in the literature and/or by patient organisations. We do not consider it is, or should be, the role of NICE to invent new terms or redefine terms differently from their use in the literature. The guideline does not exist in a vacuum. It will be referred to, quoted and read alongside other material by clinicians and patients. A new set of terminology not used elsewhere will create unnecessary confusion. This might be justified if the new terms and definitions provided greater clarity, but we have not found this to be the case.
260	Guideline	41	5	**Comment on section 'Terms used in this guideline'** The term 'pacing' does not appear anywhere in the guideline. We have read the rationale for this in the supplementary material, but are not convinced by it. We feel it is unhelpful to omit mention of the term 'pacing' altogether, given its widespread current use, and sometimes misuse, in ME/CFS. The guideline does not exist in a vacuum. Patients and clinicians will come across 'pacing' in clinics and their publications, and material from patient organisations. We suggest it would be more helpful for pacing to be included in 'Terms used in this guideline', and 1.11 'Managing ME/CFS', with a clear explanation of the different versions in use and how they

				relate to the recommendations. We suggest the term symptom-contingent, (or symptom-based, or symptom-guided) pacing (recommended), and its contrast to schedule-contingent or activity-contingent pacing (not recommended), as being particularly helpful. Terms such as 'pacing up' (a version of GET) and 'adaptive pacing' (PACE trial structured version) need to be explained as unhelpful. Including explanations of these terms in the guideline may go some way to address the issue raised by the Committee of the range of interpretations and lack of a standard definition for the term ‘pacing’ (Evidence Review G, P.322). It is also important to make clear that the version of 'pacing' used in pain clinics is more like graded exercise therapy and should not be recommended for people with ME/CFS.
261	Guideline	41	5	**Comment on section 'Terms used in this guideline'** We are not persuaded by the selection and definition of a mix of new and old terms used in the guideline to describe the effects of activity on symptoms and function. The terms used - energy envelope, fatigability, post exertional symptom exacerbation, post exertional malaise, flare and relapse are not clearly delineated. Nor are they defined in ways in common use in the literature or by patient groups. We are very concerned that this will lead to more confusion and misunderstanding of the effects of activity on people with ME. We suggest the following alternative simpler version: 'Energy envelope' be abandoned as a confusing metaphor, and simply described in plain language, as and when needed, as the amount of activity a patient is usually able to sustain on an ongoing basis without triggering significant worsening. 'Fatigability' be used to refer to the effect of increase in symptoms and abnormally rapid diminution in performance during and immediately after any and all daily physical and cognitive activity. 'PEM' (Post Exertional Malaise) be defined as the, often delayed, effect of activity beyond the person's capacity at the time, leading to a significant increase in symptoms, and a significant reduction in function, lasting usually several days to weeks and sometimes longer. This version of PEM is in common use in some research, by some clinicians and by patient organisations. We recommend that Post-exertional symptom exacerbation ('PESE') be removed as unnecessary and leading to confusion. 'PESE' introduces untested terminology that health care practitioners will not be familiar with, may be misinterpreted as post-exertional fatigue experienced by people with some other conditions, and does not convey the increase in generalised unwellness and significant reduction in function that accompany other symptom

				worsening. We recommend the removal of the term 'flare'. It is unclear from the definition where 'PESE' and 'flare' would lie in relation to fatigability and PEM. 'Flare' is not in general use in the ME/CFS literature. Where it is used in the guideline we recommend it be replaced by a description such as 'worsening of symptoms' if it is meant in the general sense of any downward fluctuation, and 'PEM' or long-term deterioration for those specific phenomena. We recommend removal of the term 'relapse' as this is usually understood to mean deterioration after a period of improvement or remission which is not the common pattern in ME/CFS.
262	Guideline	41	9-11	**Activity** Suggest adding: 'For people with very severe ME/CFS, significant activities include, for example, swallowing and listening to quiet speech'.
263	Guideline	42	4-6	**Energy Envelope.** We find the definition unclear. We recommend that 'Energy envelope' be abandoned as a metaphor many find unhelpful, and simply described in plain language, as and when needed, as the amount of activity a patient is usually able to sustain on an ongoing basis without triggering significant worsening. Further, 'energy envelope' is associated in ME/CFS literature with a particular approach to energy management that is not universally supported.
264	Guideline	42	7-9	**Energy Management**: We have recommended that the term 'energy envelope' should not be used in the guideline. We recommend the introduction of the term 'symptom contingent pacing' as a more helpful approach to energy management.
265	Guideline	42	14-24	**Fatigability** We are pleased to see this term spelled out separately from the usual 'fatigue' in diagnostic criteria. It should be defined as well as listing its key features, which should focus on the immediate and direct physical and cognitive effects. Delete lines 16-20 which are features of ME/CFS, not specific descriptors of fatigability. Suggested alternative definition: **Fatigability** is the increase in symptoms and abnormally rapid diminution in performance that occurs during any physical or cognitive activity, often with an abnormally slow recovery period after stopping the activity. Symptoms of fatigability include: • rapid muscle fatigue in which strength or stamina are lost quickly after starting an activity, causing sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently. The sensation of being ‘physically drained’. In some cases, accompanied by increasing muscle pain. • cognitive fatigue that slows and worsens cognitive function.
266	Guideline	42	16	Remove 'especially in the early days of the illness'. This does not conform with our members' experience. Many continue to have 'sick or flu-like fatigue' for decades. We question whether there is sound evidence to support this.
267	Guideline	42	17-18	Remove the item about sleep. The sleep effects may be present even without any activity, so should not be listed as part of the fatigability

				definition. We don't know what 'hypervigilance during sleep' means, and 'tired but wired' may occur during the day and prevent sleep, and is associated more with episodes of PEM, rather than a daily symptom of fatigability.
268	Guideline	42	21	Suggested rewording: 'cognitive fatigue that slows and worsens cognitive function.' Not all people have permanent cognitive difficulties, but most or all do experience cognitive fatigability.
269	Guideline	42	22	After muscle fatigue add '(accompanied by increasing muscle pain for some people with ME/CFS) '
270	Guideline	42	25-29	**Flare** It is not made clear in what way flare differs from Post-exertional symptom exacerbation (PESE) and Post Exertional Malaise (PEM), or from the fluctuations in daily ME/CFS. Flare is not a term commonly used in the literature, or widely used as a specific term by people with ME/CFS. The term increases confusion and is redundant. We strongly recommend that it not be used in the guideline. Where 'flare' is used in the guideline we recommend it be replaced by a description such as 'worsening of symptoms' if it is meant in the general sense of any downward fluctuation, and 'PEM' or ‘prolonged deterioration’ (recommended term instead of 'relapse') for those specific phenomena.
271	Guideline	43	2	'change in treatment' is unclear. It should be made clear that this does not refer to an ME/CFS treatment, since there are none.
272	Guideline	43	3-8	**Management plan** We consider the term ‘medical care plan’ to be more appropriate than ‘management plan’. The former makes it clear that it is a plan to deliver care. The term ‘management plan’ implies that the person with ME/CFS and their condition are to be managed. All uses of ‘management plan’ throughout the draft guideline should be changed to ‘medical care plan.
273	Guideline	43	6	'Add - 'if wanted by the person with ME/CFS' after 'other assessments and plans'. The person with ME/CFS should retain control of plans for their life.'
274	Guideline	43	7	In defining the management plan (medical care plan) we suggest changing 'cognitive behavioural therapy' to 'psychological support'. There is no research evidence that people with ME/CFS find CBT the most helpful modality of psychological support - of those who want psychological support, many prefer counselling. Nor is there any evidence that CBT therapists are the most appropriate health professionals for helping patients with energy management. This is likely to be better done by a specialist nurse who can also discuss medications and other approaches for symptom management.
275	Guideline	43	9-13	**Mild ME/CFS** This description of mild ME/CFS really only describes very mild ME/CFS.
276	Guideline	43	11	Even with mild ME/CFS, people are unlikely to be able to sustain full-time work without accommodations and substantial assistance at home. They are likely to need to reduce employment or education to flexible working or part-time, with some or all work or study done mostly from home.
277	Guideline	43	13	change to 'rest on weekends to recover from the week'. We don't think the word 'cope' is appropriate as it has connotations of not coping emotionally

278	Guideline	43	14-19	**Moderate ME/CFS** Some of the points listed are symptoms of ME/CFS experienced at all severity levels, not specific to moderate severity. We wonder why these specific symptoms were singled out for inclusion in this definition. The definition would be clearer if it focused on the level of functional capacity.
279	Guideline	43	15	add 'and most people of moderate severity are housebound most or all of the time' after 'have reduced mobility'
280	Guideline	43	16	Delete: 'may have peaks and troughs'. This applies to all levels of severity, we are not clear why it is specified here.
281	Guideline	43	18	Replace: 'need rest periods, often resting in the afternoon for 1-2 hours' with 'need several hours rest during the day'. The afternoon rest time is too specific, and not evidence based. It may be an artefact of misguided attempts at sleep hygiene advice limiting night time sleep.
282	Guideline	43	19	Delete. Poor quality sleep is a feature of all severity levels of ME, not specific to moderate ME/CFS, and is covered in symptom lists elsewhere.
283	Guideline	43	20-26	**Orthostatic intolerance** This definition confuses symptom and cause. Suggested replacement: '*Orthostatic intolerance means an increase in symptoms when upright, or an inability to remain upright. In some patients with ME/CFS, POTS or postural hypotension may be the cause of OI but it is not established that blood flow hypotheses explain all OI in ME/CFS.*'
284	Guideline	43	27	**Physical activity** We agree that this is a good general definition of physical activity for the healthy population. It would be helpful to adjust the definition to recognise that even very minor movements can have great significance to a person with severe or very severe ME/CFS. We suggest adding at the end of the definition: *'For some people with ME/CFS, physical activity as trivial as cleaning teeth and a brief conversation can account for a substantial proportion of the daily activity level that is possible.*'
285	Guideline	44	17	As physical maintenance is concerned with mitigating deconditioning and its effects, a clear statement should be added that ME/CFS is not caused or perpetuated by deconditioning and physical maintenance will not treat or cure ME/CFS or its symptoms.
286	Guideline	44	18-22	**Post-exertional symptom exacerbation** This new term Post-exertional symptom exacerbation (PESE) should not be used. We support the continued use of the well-recognised term 'post-exertional malaise' (PEM). There is a strong argument for including the word 'malaise' which has the specific medical meaning of feeling very unwell, and describes PEM well. Guidelines should work with available evidence, rather than inventing new terms. PEM is the term used in international ME/CFS research and it is the term used in a wide range of training and information resources. The given definition of PESE is non-specific and could easily be misinterpreted as the same as post exertional fatigue, since it does not specify which symptom or symptoms are exacerbated, nor does the term convey the key

				facts that during PEM the person with ME feels both much sicker and has much reduced ability to function. We suggest the following alternative definition: **Post-exertional Malaise:** When a person with ME/CFS exceeds the activity level they are currently able to sustain daily - either due to a single high energy activity, prolonged exertion, or the cumulative effect of activities with too little rest - this triggers an episode of post-exertional malaise (PEM). The onset of PEM may be delayed by 12-48 hours, and it lasts at least a day, usually several days to weeks or longer. A bad bout of PEM or series of episodes of PEM may be followed by a prolonged deterioration to a more severe level of ME/CFS. The symptoms of PEM are: - a marked reduction in function, often confining the patient to bed; - 'flu-like' malaise, with additional symptoms such as nausea, loss of appetite, sore throat, headache, dizziness, and acute sensory sensitivities; - a marked increase in, or changes to daily symptoms such as orthostatic intolerance (OI) and disordered sleep; - marked increase in the symptoms of physical and cognitive fatigability; - profound exhaustion; - a reduced threshold for incurring further PEM.
287	Guideline	44	23-29	**Relapse** We recommend removal of the term 'relapse' as this is usually understood to mean deterioration after a period of improvement or remission. People with ME/CFS may not have experienced any improvement whatsoever prior to deterioration of their condition. We recommend a more appropriate term, such as 'long-term deterioration' or ‘prolonged deterioration’ be used instead.
288	Guideline	45	11-16	**Therapy blueprint** We suggest this term be deleted. We question the need for a 'therapy blueprint' separate from the patient's management plan. We do not expect that most patients will need or want 'therapy' in order to manage their activity and symptoms, though they may want support and information about helpful resources and strategies for activity management. There is no evidence that this has to be provided by a 'therapist'. A specialist nurse may be more appropriate. The phrase 'therapy blueprint' only appears once in the guideline in a section we are recommending should be deleted. It is a CBT tool and as there is no evidence for dysfunctional thoughts having anything to do with the aetiology or pathogenesis of ME/CFS it should be removed.
289	Guideline	45	15	Delete 'goals for the future'. We consider it wholly inappropriate for people with ME/CFS to be encouraged to make and record goals for the future. ME/CFS is a serious chronic illness for which it is impossible to predict what goals, however small, might be achievable. This sets the patient up for failure. If what is meant is goals to more effectively manage their activity, get sufficient rest, or make more use of available help and support, then that should be specified.

290	Guideline	45	17-20	**Unrefreshing sleep** Delete the sentence: 'Unrefreshing sleep is described as a light sleep'. It is not evidence based, not described this way in any of the diagnostic criteria and does not reflect our members' experience.
291	Guideline	45	24-26	Diagnostic tests. We agree this is important.
292	Guideline	45	23	Our members have suggested the following could be added as important areas of research: Assessments of severity; upright hours Epidemiology - increase understanding of gradual onset cases; illness trajectory Treatments - including dose response trials Tired but wired phenomenon Pain relief - how effective standard pain management strategies and medications are for the pains experienced as a symptom of ME/CFS, and whether there are treatments patients find more helpful Orthostatic intolerance - which investigations are appropriate and should be included in diagnostic and review assessments, for example, tilt table testing for POTS and orthostatic hypo- or hypertension.
293	Guideline	46	1-3	Core outcome set We agree this is important. We suggest adding: '*including objective measures and ones that can be automated such as wearable technologies and apps.'* We also think some current questionnaire-based outcome measures are clearly unfit for purpose and it is just as important that this be recognised and their use discontinued.
294	Guideline	46	4	We suggest adding a further, and important, section: **'Recommendations of areas where further research is NOT justified'** These would include: 1. **Activity based therapies** Treatment trials of activity or energy management that include fixed or flexible incremental increases in daily activity or exercise. It has already been demonstrated that these approaches do not lead to improved health or function, and that many patients report worsening symptoms. Inventing yet another variation on this approach should not be used to justify further such research. It would be unethical to undertake any research that includes risking pushing patients into significant deterioration as part of a treatment program, regardless of what physiological model it is based on. We recommend further that any such trials currently in progress should be discontinued, and any further funding agreed for such trials should be withdrawn. 2. **Psychological therapies** It has been established that psychological therapies such as CBT are ineffective in improving the health or function of people with ME/CFS. We are aware that some therapists in current practice are introducing variations such as Acceptance and Commitment Therapy as treatments. We recommend that this practice be discontinued, and further trials based on such therapies for ME/CFS not be funded.

				3. **The role of personality factors in ME/CFS onset, perpetuation and treatment resistance** Our members review a regular stream of research investigating a range of personality flaws in people with ME/CFS. This research is almost always done extremely poorly and, while not finding any evidence of such predisposing flaws, generally manages to conclude with an inference that such flaws do exist and that further research of this type is required. Our members find this research offensive and stigmatising. Given that nothing of value has been produced from this type of research after years of effort, and research funds have been wasted and substantial harm has been caused, we ask that funders do not continue to support it. We recommend adding a note that any funding process should require that any submitted ME/CFS research proposal include a letter of support from a major UK patient charity.
295	Guideline	46	5-7	Diagnostic criteria Suggested wording: '*Case definition for clinical use: Research which of the existing case definitions is, pending the development of a biomarker, most appropriate for use in clinical diagnosis and should be used in future NICE guidelines.*' We note that the guideline committee have modified an existing diagnostic case definition (IOM -Institute of Medicine), making it more restricted, with cognitive difficulties mandatory for diagnosis, whereas the IOM criteria list cognitive difficulties as an alternate core symptom with orthostatic intolerance. We are concerned that this decision was based only on the experience of the small number on the guideline committee, not on peer reviewed research. This will result in the exclusion from ME/CFS diagnosis of people, including some of our members, who fit the IOM criteria and some other criteria, and who would benefit from being recognised as having ME/CFS and the management and care recommended in the guideline. Missing out on diagnosis may lead to harm through mismanagement.
296	Guideline	46	8-10	Self-monitoring management strategies We agree this is important. It would be worth adding '*that are manageable by people with very limited energy and cognitive problems*. And add '*including ways to track activity levels and symptoms, ideally automated, and requiring little or no subjective input, such as wearable technologies and apps*'.
297	Guideline	47	1-3	Sleep management strategies While we agree that sleep is a problem for many people with ME/CFS, it should not be assumed that standard 'sleep management' strategies are appropriate or effective. This section should include research into which sleep medications people with ME/CFS find most effective.
298	Guideline	47	4-6	Dietary strategies We do not think this section should be prioritised. People with ME/CFS have tried a wide range of diets and many eat very healthily, but it has no impact on their illness. While it is true that some people with ME/CFS have food sensitivities, these need to be treated on a case by case basis as a comorbidity.

299	Guideline	71	9	**Context** We recommend that the Context, currently placed near the end of the draft guideline, be moved to a more prominent position at the beginning. This would be in line with the multiple sclerosis guideline where the Context is on page 4. A lot of the information in it about how it affects patients is vital information that should be part of an introduction to the whole guideline, along with a clearer and more comprehensive list of frequently occurring symptoms and descriptions of severity levels, prevalence of each and level of function and needs of each. There is so little knowledge about ME/CFS among clinicians, therapists and patients that we really need a clear exposition of what it is and how it affects people at the start of the guideline. Otherwise inaccurate assumptions will be made.
300	Guideline	71	10-14	Move the detail of naming to the terms section. There is no need to cover this in the context; instead it can just be noted that ME/CFS is the term now used for a condition that has also been called myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). Lines 10-14 could then be replaced with: 'Although its pathophysiology is not yet understood, ME/CFS is a well-defined condition with the hallmark clinical feature, post-exertional malaise (PEM)'
301	Guideline	71	13-14	Suggested wording: 'Many people with ME/CFS consider the name 'chronic fatigue syndrome' inaccurate and trivialising because symptoms include much more than fatigue, and because fatigue is often wrongly assumed to be the same as tiredness.' We suggest this change because the use of the words 'simplistic' and 'judgemental' are value laden words that are in danger of reinforcing stereotyping of people with ME.
302	Guideline	71	17	Remove the word 'complex'. It gives the false impression that patients are complex and difficult. The rest of the sentence is sufficient without it. Replace 'multi-system' with 'with symptoms affecting multiple body systems'. While it is clear that there are multiple symptoms, we don't have evidence of pathology on multiple systems.
303	Guideline	71	19	Remove the reference to 'emotional wellbeing', it is adequately covered by 'quality of life'. Singling it out gives the misleading impression that people with ME/CFS are likely to need psychological therapy. This may divert from the more practical help needed, and give undue prominence to the provision of CBT or other therapy as a core part of ME/CFS treatment.
304	Guideline	71	20-21	Delete the sentence 'Everyday life for people with ME/CFS, their family and carers is disrupted and unpredictable'. Disrupted and unpredictable are not the best descriptors of ME/CFS and the context notes that the condition has 'personal, social and economic consequences' and a 'low quality of life'. Change 'unemployed' to 'too sick to undertake paid employment or formal education', to make it clear that it is ill heath, not idleness, that means they are not working.
305	Guideline	72	7-9	This acknowledgement of the harm that has been caused by lack of belief is welcome and needs to be emphasised in a more prominent position in the guideline, reinforcing the importance of the whole context section moving to the beginning of the guideline. It is not only that people with ME/CFS are dissatisfied with care and disengage from services. In many cases

				there are no adequate or appropriate services for them to engage with. Using the terms 'dissatisfied' and 'disengage' applied to patients can be misinterpreted as fussiness on their part. We suggest a change of emphasis from patients to putting the onus on providers. Often there is nothing suitable provided that patients can opt into, thus preventing equitable access to care. This is particularly vital for people with severe and very severe ME/CFS who need thorough understanding of and sensitivity to their needs.
306	Guideline	72	7-9	Add: '*For some people with ME/CFS, the impact of disbelief has been far greater than dissatisfaction with care and disengagement from services. Disbelief from health and social care professionals about their condition and related problems has led to misdiagnosis with mental health disorders, inappropriate involvement of mental health workers, instigation of mental health proceedings and in some cases detainment under mental health law.*'
307	Guideline	72	10-11	We appreciate the inclusion of the particular needs of children, but this section underplays the seriousness of ME/CFS. Add: '*Some children and young people cannot attend school at all and may be too sick to undertake any education at home. Misunderstanding about ME/CFS has led to families facing social services enquiries, accusations of child abuse or neglect, or FII, and threats of children being removed from families if they refuse for their child to undertake a prescribed therapy with poor or no evidence of effectiveness in very sick children.*'

Insert extra rows as needed

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