

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

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.</p> <p>In addition to your comments below on our guideline documents, we would like to hear your views on these questions:</p> <ol style="list-style-type: none">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.) <p>See Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>
<p>Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>Action for M.E.</p>

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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:		Sam Bromiley		
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.
Example 1	Guideline	16	45	We are concerned that this recommendation may imply that
Example 2	Guideline	17	23	Question 1: This recommendation will be a challenging change in practice because
Example 3	Guideline	23	5	Question 3: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact.....
Example 4	Guideline	37	16	This rationale states that...

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Example 5	Evidence review C	57	32	There is evidence that ...
Example 6	Methods	34	10	The inclusion criteria ...
Example 7	Algorithm	General	General	The algorithm seems to imply that ...
1	Guideline	General	General	<p>This response is informed by:</p> <ul style="list-style-type: none"> • our Big Survey of more than 4,000 people with M.E./CFS conducted in 2019 • our NICE Draft Guideline survey of more than 1,500 which ran from November to December 2020 • our frequent and sometimes sustained contact with and support of children, young people, adults and families living with M.E./CFS across the UK, through our Action for M.E. support services. <p>We feel that this guideline is an important step forward and would like to express our thanks to the expert witnesses, guideline committee (especially the lay members) and the M.E./CFS community for engaging in every step of the process.</p> <p>Action for M.E. is pleased to see increased emphasis on the patient experience in this guideline, including a reflection of the disbelief that has been experienced. People with M.E./CFS have repeatedly stated the disbelief and harms they have experienced by healthcare professionals and this draft guideline goes some way to acknowledge that.</p> <p>We also welcome the change in direction away from inappropriate therapies like Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) being used as a treatment or cure. Because of the lack of research and evidenced treatments, strong consideration needs to be given to those with lived experience of the condition, with weight given to patient experience.</p> <p>We are however concerned with some of the definitions used in this guideline and the departure from terms used by many people with M.E./CFS, such as pacing. Patient experience tells us that this is the most useful method in managing symptoms and we feel this term should be used throughout the guideline with a definition accepted by the patient community.</p> <p>The comments detailed in our submission reflect the positives in the guideline but also detail some areas which we remain concerned about, such as:</p> <ul style="list-style-type: none"> • the need for more emphasis on the patient's voice and decision making power in the relationship with a healthcare professional

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				<ul style="list-style-type: none"> sections on physical activity which need strengthening to ensure that they cannot be misused or misinterpreted wording around the use of CBT within this guideline the lack of detail on the experiences of BAME people with M.E./CFS the lack of reference to the level of isolation people with M.E./CFS can experience.
2	Guideline	General	General	We are pleased to see more emphasis on patient choice and the role patients play in choosing the care they receive. We would like this role strengthened throughout the guidance. We would request that a summary is produced for people with M.E./CFS including options to receive it in 'easy read' and other formats.
3	Guideline	General	General	<p>M.E./CFS is a neurological disease classified by WHO ICD10 G93.3. This classification is also recognised by the Department of Health and Social Care. It is also recognised as a disease by all of the US authorities and by many researchers. It would be consistent if the term 'disease' is used throughout in place of 'medical condition' which does not reflect the impact of M.E./CFS. In our 2020 NICE Guideline Survey almost nine in ten respondents (89%) said that they would like to see NICE make clear that M.E./CFS is a neurological disease.</p> <p>Many people with M.E./CFS have faced disbelief or accusations that it is a psychological condition. A clear statement from NICE acknowledging the physical realities of M.E./CFS and supporting the WHO classification can go some way to addressing this ongoing issue.</p> <p>We request that additional information is added throughout that emphasises the isolation that is experienced by people with M.E./CFS. In our 2020 NICE Guideline Survey 73% of respondents said that having the condition makes them feel very isolated. We would like to see this highlighted with advice on how this isolation could be reduced.</p> <p>We would also like the addition of the benefits of peer support for people with M.E./CFS. 50% of respondents said that being connected with other people who have a similar experience would be helpful to them. We also see this in the Action for M.E. forums.</p>
4	Guideline	General	General	<p>Action for M.E. welcomes the recognition that GET should not be offered to people with M.E./CFS. Repeatedly patient surveys have provided evidence of the harms caused by this therapy. Action for M.E.'s Big Survey 2019 found that:</p> <ul style="list-style-type: none"> 47% of those who had GET with support from an M.E./CFS Specialist experienced a worsening effect on their health with 21% seeing no difference at all. <p>It is therefore right that this therapy is removed as a recommendation. There should still be a statement of the likely harms added to ensure people with M.E./CFS are not put at risk by health professionals who have little understanding about the condition. This is further needed because it is a big change from the 2007 guideline, we would like to ensure that GET cannot be considered an option by any healthcare professional.</p>
5	Guideline	General	General	Missing – advice on Surgery

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				<p>Surgery - it is possible for people with M.E./CFS to have major relapses after surgical operations, especially when poorly managed. Specific issues that may need addressing include; orthostatic intolerance, reduced blood volume, lowered temperature control, sensitivity to anaesthetics, and longer recovery times. Certain types of anaesthesia may need to be avoided.</p> <p>For example, detailed guidance is provided in the International Association for CFS/ME Primer, 2014 (Appendix E): https://www.iacfsme.org/assets/docs/Primer_Post_2014_conference.pdf</p>
6	Guideline	1	9	This guideline is a new guideline and not a replacement of CG53. Please correct this on the front page.
7	Guideline	2	Text box	There is evidence suggesting that M.E./CFS can be developed following a viral infection, so we would like to see this wording revised to ensure that it is recognised some people with Long-Covid or similar post-viral illnesses may be diagnosed with M.E./CFS. If the person fits the diagnostic criteria for M.E./CFS in this guideline then the information contained within must override other advice from NICE.
8	Guideline	4	3	We would like the addition of a principle that recognises that, because of a lack of biomedical research, little is known about M.E./CFS. It is essential that healthcare professionals learn from those with lived experience when overseeing their care.
9	Guideline	4	4	We would like an additional point that recognises that M.E./CFS can affect any age group. We often hear from people with M.E./CFS who have symptoms discounted because of their age.
10	Guideline	4	5	Because of the disbelief and misunderstanding that people with M.E./CFS have experienced, we would like to see the wording strengthened here. Change “ <i>can have a substantial impact</i> ” to “ <i>has a substantial impact</i> ”. We feel this is reflected in the physiology of the condition and symptoms that a person will have experienced for several weeks or months before diagnosis.
11	Guideline	4	16	<p>We strongly welcome this addition and the recognition of the injustice and disbelief people with M.E./CFS have faced. We would like to see it repeated throughout the guideline in each of the sections to ensure healthcare professionals are aware of difficulties the person may have faced in the past.</p> <p>One example of the difficulties people have faced is the continued misdiagnosis of Medically Unexplained Symptoms (MUS). In our 2020 NICE Guideline Survey we asked respondents whether they have personal experience of their M.E./CFS being misdiagnosed or incorrectly described as MUS. More than one in three of respondents have experienced this. We feel this justifies stronger wording being used in the diagnosis section that makes clear treatments typically offered by MUS services are inappropriate for people with M.E./CFS.</p>
12	Guideline	5	2	We would like to see the text here strengthened and replace “should” with “must”.

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				<p>This is because of the large number of people with M.E./CFS who have reported negative experiences with healthcare professionals. In our 2019 Big Survey we found that:</p> <ul style="list-style-type: none"> Just 28% feel they are fully/reasonably confident that their GP understands M.E./CFS and how it affects them. <p>We would also recommend an additional bullet point that details the need for additional time in appointments to allow for any cognitive/brain fog difficulties the person may be experiencing. It is essential that health professionals are patient and are led by the person with M.E./CFS.</p> <p>There should be a further bullet point ensuring that Health Professionals ensure that the person with M.E./CFS understands the options available to them and that they have the power to choose which approach they would like. It is essential that the health professional has informed consent at every stage of the relationship. (Montgomery vs Lanarks Health Board 2015 UK Supreme Court Judgement 11)</p>
13	Guideline	5	5	<p>In our 2020 Big Survey we found that 64% of respondents do not currently see any health professional about their M.E./CFS. It is therefore important that health professionals know they will need to rebuild trust and this should be reflected in the wording here.</p>
14	Guideline	5	12	<p>Regular monitoring of people with M.E./CFS is important and should be maintained in this guideline. The current guideline says: "Regular, structured review should be undertaken for all people with CFS/ME." (1.8.1.1)</p> <p>People with M.E./CFS often experience a fluctuation of symptoms which would previously not be investigated due to a one-off examination at the start of their diagnosis. This is important to rule out other conditions, which could be having an adverse effect on their symptoms.</p> <p>This would also maintain a relationship between the patient and a healthcare professional. In our 2019 Big Survey we found that almost two thirds of respondents do not see any healthcare professional about their M.E./CFS</p>
15	Guideline	6	7	<p>It is essential that this section stays so that healthcare professionals know they need to understand severe M.E./CFS and the special accommodations that must be made.</p>
16	Guideline	7	4	<p>Delete 'may'. Insert 'are likely to'.</p> <p>The reason for this is to ensure that healthcare professionals know to expect that this support is needed and offer the right amount of information to a person with M.E./CFS or their carers. Our 2019 Big Survey found that just 15% of respondents identifying as severely affected had been given information on how to apply for Social Care.</p>
17	Guideline	7	8	<p>We feel this section should be elaborated upon so it is clear that aids and adaptations are not just about mobility but reducing the burden of daily living on a person's ability. For example, electric wheelchairs or mobility scooters with the</p>

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				possibility for the carer to control the direction, manual wheelchairs, sunglasses, blue light blocking glasses for screens, ear plugs, shower or kitchen stool, hoists, stair lifts, pressure relieving mattress, hospital style beds, aids to help with hair drying, speech to text computer software, blackout blinds, automatic or adapted cars, blenders for making food less effort to chew, drink with a straw as mugs are too heavy to lift.
18	Guideline	7	22	<p>We support the addition of risk assessing interactions with those with Severe ME. It is important that alongside this the health professional has a demonstrable understanding of M.E./CFS and how it affects the person. Our 2019 Big Survey said that:</p> <ul style="list-style-type: none"> 63% of respondents who identified as being severely affected said that they are not very/not at all confident that their GP understands M.E./CFS or how it affects them.
19	Guideline	8	1	We are pleased with changes made to this section to recommend early diagnosis.
20	Guideline	8	9	We would like to see the addition of baseline investigations as it was in the 2007 CG53. This would give patients the knowledge of which investigations should be offered to them so they can challenge the healthcare provider should they not be receiving this. It would also ensure parity between healthcare professionals and the investigations they undertake.
21	Guideline	8	16	<p>We feel this is slightly misleading and needs rewording. One respondent to our 2020 NICE Guideline Survey said,</p> <p><i>“I had a very specific and sudden onset of ME directly after glandular fever and had a new symptom appear suddenly years into my illness which was not listened to or investigated and instantly lumped in with ME. Some people with ME do not have a specific onset to their ME but a gradual one they struggle to pin point. They may have also already suffered for years, as I did, before a diagnosis, making things harder to remember and pinpoint.”</i></p>
22	Guideline	8	17	<p>It is right that post-exertional symptom exacerbation is recognised as a defining symptom of M.E./CFS. Our 2019 Big Survey of people with M.E./CFS emphasised the commonality of this symptom with 99% of the 4,038 respondents experiencing this following mental or physical activity.</p> <p>It would be helpful for NICE to highlight the importance of using post-exertional symptom exacerbation in both clinical and research guidance. This would ensure there is alignment with those being diagnosed with M.E./CFS and the research studies being undertaken.</p>

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				<p>We also believe that ‘unrefreshing sleep which may include’ could be replaced by ‘unrefreshing sleep and/or sleep disturbances which may include....’ so that it encompasses everyone’s experiences.</p> <p>We would also like to see a clear definition of “debilitating fatigability” to ensure it is not misconstrued as ‘tiredness’.</p>
23	Guideline	9	2	<p>We are concerned that the list is not comprehensive and there are some omissions which are common in people with M.E./CFS such as visual problems. Evidence for such:</p> <p>https://pubmed.ncbi.nlm.nih.gov/8201170/</p> <p>https://pubmed.ncbi.nlm.nih.gov/27799582/</p> <p>https://pubmed.ncbi.nlm.nih.gov/24187048/</p> <p>https://www.researchgate.net/publication/327074772_Visual_Aspects_of_Reading_Performance_in_Myalgic_Encephalomyelitis_ME</p> <p>https://www2.le.ac.uk/departments/npb/people/ch190</p> <p>We would also like to see to addition of gastrointestinal symptoms which are referred to on Page 6 Line 22 for those with severe M.E./CFS.</p>
24	Guideline	9	4	<p>It should be noted that there is no NICE Guideline for orthostatic intolerance so more information is needed here. They should also be aware of Postural Tachycardia Syndrome, Neurally Mediated Hypotension and Orthostatic Hypotension.</p> <p>The draft guideline says that the medicines usually prescribed for orthostatic intolerance can worsen other symptoms in M.E./CFS - this needs to be much better explained, with specific comments about the various different types of medicines (beta blockers, volume expanders, vasoconstrictors, etc.).</p> <p>There should also be a set of final recommendations.</p>
25	Guideline	10	9	<p>It is essential that healthcare professionals offer to engage with the child’s place of education or training as soon as possible to ensure reasonable adjustments can be made. This early intervention can support a child in staying in education and/or prevent symptom exacerbation from pressures to maintain education.</p>

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				<p>Throughout the guideline there should be greater emphasis on the need to rest and not push through activity, whether physical or cognitive. The section needs this addition to ensure that it goes hand in hand with participating in education and learning. We would like it reiterated that children should be encouraged to find a balance between education and social/family life.</p> <p>We would like to see a recommendation that, in communication from the healthcare professional to the education setting, they stipulate the importance of the school/college having a Medical Conditions Policy which will set out commitments in how they will support the person with M.E./CFS. Reference for this is the Department for Education (Dec 2015) Supporting pupils at school with medical conditions: statutory guidance for governing bodies of maintained schools and proprietors of academies in England.</p>
26	Guideline	11	4	<p>In our 2020 NICE Guideline Survey we asked respondents whether they have personal experience of their M.E./CFS being misdiagnosed or incorrectly described as medically unexplained symptoms (MUS). More than one in three of respondents have experienced this. We feel this justifies stronger wording being used in the diagnosis section that makes clear treatments typically offered by MUS services are inappropriate for people with M.E./CFS.</p> <p>We also asked people if they supported the change in diagnosis time to three months for adults. Two thirds (68%) supported this changes with 25% saying they had no strong feelings.</p> <p>We would like it recognised that in practice it has taken people with M.E./CFS significant time to get a diagnosis. In our 2019 Big Survey we asked how long after developing symptoms did they get a diagnosis.</p> <ul style="list-style-type: none"> • Just 3% said 0-3 months • 13% said 4-6 months • 19% said 7-12 months • 59% said over a year
27	Guideline	11	7	<p>After 'management' insert 'and support'</p> <p>It should also be recognised that there is a lack of specialist services offering evidenced approaches for people with M.E./CFS and therefore care may be required by a GP. We therefore recommend that GP surgeries identify a lead GP who will specialise in managing and supporting people with M.E./CFS.</p>
28	Guideline	11	13	<p>There is considerable variation in the specialist services offered to people with M.E./CFS with some choosing to travel long distances to see health professionals. This should be reflected in this section or in referral to ensure patients have a choice who they see and are supported to travel to visit the most suitable specialist.</p>
29	Guideline	12	25	<p>We would like the wording here changed to reflect that not all methods in the link are for managing symptoms.</p>

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30	Guideline	13	12	<p>It is right and essential that people with severe or very severe M.E./CFS are offered a home visit. This should be extended to those who can evidence that a visit to a surgery or hospital will have a worsening effect on their health. As the condition can fluctuate, there will be some who are mild/moderate but will become severely affected by the physical and cognitive activity of visiting a healthcare setting.</p> <p>It should also be recognised that those who are very severe may only be able to manage a short home visit. Further investigations or queries can be carried out through text or phone calls with the person with M.E./CFS or their carers. We recommend that this flexible approach be adopted by M.E./CFS services to ensure there is a variety of delivery mechanisms to meet need.</p>
31	Guideline	13	14	<p>We would like the addition of a section that recognises the difficulties people with M.E./CFS can experience when applying for disability benefits and the role a healthcare professional should have in this process. Many of those who are unable to work face an uphill battle when asking for this support and proactive communication can reduce stress and symptom exacerbation. We have heard from people with M.E./CFS who struggled to get their doctor to write a supporting letter which then worsens their quality of life.</p>
32	Guideline	14	18	<p>At the end insert: <i>'and are worsened by exertion'</i></p>
33	Guideline	14	28	<p>We would like the addition of common triggers here such as points in the menstrual cycle and surgery.</p>
34	Guideline	16	6-11	<p>We have concerns that a Safeguarding section within this Guideline may, in some cases, lead to more harm. We would like the language changed to make it clear the reason for the inclusion of this section is because of inappropriate referrals that have been made due to a lack of understanding about the condition.</p> <p>In our 2017 survey of families of young people with M.E.:</p> <ul style="list-style-type: none"> • 90% of respondents were concerned that professionals involved with their child did not believe them • one in five (22%) said a safeguarding/ child protection referral had been made against them <ul style="list-style-type: none"> ○ nearly half of these referrals related to claims of fabricated/induced illness or FII (previously known as Munchausen's by Proxy), which occurs when a parent or carer exaggerates or deliberately causes symptoms of illness in the child; this heightened frequency of FII claims sits widely outside the national prevalence rate • 70% of all cases were dropped within a year <p>We agree with comments by Forward ME regarding this:</p> <p><i>Replace 2 paragraphs with the following:</i></p>

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				<p>1.7.1 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 abuse or neglect. In the case of children, ME/CFS should not be mistaken for very rare conditions such as Munchausen’s syndrome by proxy or with fabricated or induced illness.</p> <p>1.7.2 Safeguarding assessments in people with confirmed or suspected ME/CFS should be carried out and overseen by health and social care professionals who have training and experience in ME/CFS.</p>
35	Guideline	18	10	<p>We are pleased to see this statement, however, it needs to be strengthened. People can experience a fluctuation of symptoms over the course of a few hours or days, sometimes triggered by unexpected emotional or physical events. We suggest changing the paragraph to:</p> <p><i>“Do not discharge someone who misses appointments. Contact them to explore why they could not attend and how to support them in a way that takes into account their functional ability.”</i></p>
36	Guideline	18	15	Remove the word ‘fear’ and replace with ‘risk’.
37	Guideline	18	24	In the line ‘supporting their applications for aids and appliances’ add in ‘and financial support’.
38	Guideline	20	19	We welcome these recommendations but would like to see the addition of information and support in applying for a Blue Badge, recognising the advantages this would have on a patient’s ability to plan activity and rest.
39	Guideline	20	23	We welcome this recommendation.
40	Guideline	21	1	<p>We would like to see examples of the type of adjustments a workplace can make to support a person with M.E./CFS in employment. eg. working from home, flexible hours, reduced hours, speech to text, a quieter working space, a space to rest when needed, transport help, parking space closer to the building, adaptations to the lighting levels or type of lighting used, blue light blocking glasses.</p> <p>Make clear that adjustments should be realistic, achievable and solutions-focused based on need, with no employee taking on more than they can manage.</p>
41	Guideline	21	5	At end add: ‘full or part time. Return to these activities is likely to be gradual, if possible at all. Pushing to continue to work or attend school or further education is likely to result in lasting illness and disability.’
42	Guideline	21	12	Include ‘Department for Work and Pensions.’
43	Guideline	22	10-12	We are pleased to see children being advised to find a balance between education and social/family life.
44	Guideline	22	13	We agree there needs to be a multidisciplinary approach but it may be inappropriate for the specialist care of a person with M.E./CFS to be led by a Psychiatrist or Psychologist. This should be reflected in the statement. Patient surveys

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45	Guideline	23	4	At end add: 'if and when able'
46	Guideline	23	7	We support this recommendation.
47	Guideline	23	12	We feel that the addition of a named contact for children and young people is an important step. We would like the recommendation changed slightly to reflect the child or young person should be involved in choosing the named professional. This is also reflected in Evidence Review I page 25 Line 10.
48		24	1	We are concerned that there are no references to the complimentary approaches that fall outside of mainstream healthcare/medicine. People who responded to our 2019 Big Survey informed us that they use these methods as part of a management strategy. As these therapies are being sought out by people with M.E., we would like reference to it in the guideline so healthcare professionals are aware of the need to ensure they are kept up to date with any therapies being used by a person with M.E./CFS.
48	Guideline	24	4	We feel this should be reflected in the research recommendations.
49	Guideline	24	6	<p>We support emphasis that energy management is not curative/a form of treatment. It is about energy management and operating at your baseline. It is essential that NICE recommend additional training for medical professionals on this. In our 2020 NICE Guideline Survey 74% of respondents agreed with the phrase "I am concerned that my GP would not have the expertise to support me to develop a pacing/energy-management plan."</p> <p>Almost four out of five respondents (79%) also said that they would like to see more detail about what energy management means.</p> <p>We would recommend using the term 'Pacing' rather than energy management. Respondents to our survey describe this as a quicker and easier term to grasp, with greater clarity on how it works. It should also be recommended that advice on pacing/energy management from the perspective of a person with M.E./CFS should be provided to demonstrate real life examples. In our 2020 NICE Guideline Survey, we asked respondents for their opinion on this and 62% said they were likely to refer to this approach as pacing.</p> <p>It should also be acknowledged that this approach is still challenging for people with M.E./CFS. In the survey 60% of respondents said that they struggle with pacing/energy management, but it's still the thing that has been most useful.</p>
50	Guideline	24	15	We recommend inserting information about 'post-exertional symptom exacerbation' into this line to demonstrate the risk of overexertion. It also needs to be clear than this onset may occur after hours or even days so extra care must be given.
51	Guideline	25	3	Please replace 'does not assume' with 'recognises that'. Without this change, there is concern that this could be misinterpreted.

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52	Guideline	25	5	We would like the wording around 'goals' clarified. People with M.E./CFS should be informed that a goal could be reducing activity levels to achieve symptom stabilisation.
53	Guideline	25	21	<p>We would like to see this sentence altered to include references to both physical, emotional and cognitive activity. It should also be clear that this activity could include something as small as sitting up or looking at a clock, whereas for some it may be more of an activity yet have the same level of 'payback'.</p> <p>It is very important to note that "activity" does not just mean physical activity. Mental activity such as reading a book, watching television, having a conversation in person or by phone, also counts – as will emotional activity such as receiving bad news.</p> <p>Some people with M.E./CFS tell us that emotional activity can be the most draining, and the hardest to measure and control.</p> <p>Physical, mental and emotional exertion counts as activity, even in small amounts. Examples include walking, reading a book or having a difficult conversation with a friend or family member.</p>
54	Guideline	26	1.11.8	<p>The wording in this section is not appropriate and could lead to misinterpretation and potentially a form of graded exercise therapy being given to a person with M.E./CFS. The next comments are for the following points in the guideline:</p> <p>“• are ready to progress their physical activity beyond their current activities of daily living • would like to incorporate a physical activity programme into the management of their M.E./CFS”</p> <p>These points give the impression that this is an inevitability and that all people with M.E./CFS should be ready to increase activity at some point. This interpretation can lead to pressure from a healthcare professional for a person with M.E./CFS to push beyond their capabilities. In order to protect people with M.E./CFS from harm there are changes needed to this section. In our 2020 NICE Guideline Survey, we asked respondents about the effect physical activity as part of self-management has had on their health. Half of respondents said it had a worsening effect.</p> <p>We suggest:</p> <ul style="list-style-type: none"> • Greater emphasis on patient choice. It should be made clearer that it is up to the person to choose if they wish to make any changes. • Removing the two bullet points and replace with: <ul style="list-style-type: none"> ○ Choose to make any changes to their activity and energy management plan.
55	Guideline	26	8	We are pleased to see a section highlighting severe/very severe M.E./CFS. One respondent to our 2020 Draft NICE Guideline Survey said:

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				“Severe and very severe ME can seem like a different illness to the mild form. Many people and medical professionals only see the "walking wounded" and no idea why a more severe patient can't make it into the surgery for example, and don't believe the patient's explanation. Severe patients should be able to refer doctors to easily accessible guidance.”
56	Guideline	26	16	We feel that some wording should be added to this section to ensure the recommendations are considered in line with other advice given throughout this guideline. We therefore suggest a caveat reminding health professionals to ensure all activity undertaken, including that of daily life, should be within the energy envelope.
57	Guideline	26	17	Consideration should be given on the severity of the condition when producing a physical maintenance plan in partnership with the person with M.E./CFS. We would like to see emphasis at this point that this is about maintenance as opposed to increasing strength and fitness.
58	Guideline	27	3	We agree with this recommendation
59	Guideline	27	8	We agree with this recommendation
60	Guideline	27	14	We believe that families should be given information about the key symptoms. This would ensure they are better able to support the patient but also can look out for new symptoms, which might be a sign of a co-morbid condition.
61	Guideline	27	20	In our 2020 NICE Guideline Survey, we asked respondents to choose which element of the draft NICE Guideline was most important to them. Almost 80% said that <i>‘the clear advice people with M.E./CFS should not be offered any therapy based on physical activity or exercise as a treatment of cure for their M.E.’</i> was the most important part. In addition to this, 57% said that it is important there is a strong emphasis throughout that any plan put in place to support someone with M.E./CFS must be tailored to the individual, by the individual, with appropriate support from a professional with experience of M.E./CFS if needed. We would also like it clarified that unstructured AND structured exercise (as stated in the evidence review) can be harmful, even with supervision, We would like to see it repeated elsewhere in the guidance to ensure it is understood. In the NICE Survey half of respondents (50%) feel there is not enough warning about the impact of physical activity/exercise. Other respondents to our survey said: "Physical activity has only ever worsened my symptoms. I would like to see realistic examples of how this could help, based on actual M.E./CFS patients and with the acknowledgement that this may not be a suitable approach for many people with M.E./CFS (and that it should not be continued to be pushed in the event that it worsens symptoms). I also have concerns about the assumption that patients are to be supported by a therapist or doctor with knowledge or

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				<p>understanding of the condition - I have been ill for 19.5 years now, and in that time have had maybe 2 doctors who have more than cursory knowledge of M.E./CFS - and many more who continue to refuse to acknowledge that it exists."</p> <p>"I was helped enormously in the early 90's by a thoroughly competent OT. In 2010, I experienced a 4-weekly 'intensive' GET course which was full-time (9am-3pm, weekday attendance) was a personal disaster for me. I was lumped in with people with Fibromyalgia (I have Fibromyalgia also) but suffered badly, with pain and M.E./CFS crashes."</p> <p>"Some physical activity is required for the basics of living. eg chewing. Many bits of 'normal' physical activity need to be balanced and traded off against each other in a 'robbing Peter to pay Paul' manner. I've been eating recently, but have not been able to have a shower or wash my hair for over two months. Ten years since I've been to a hairdresser. Two years overdue for the dentist and four years overdue for the optician."</p>
62	Guideline	28	1-11	We strongly support these statements in the guideline and the emphasis that it should not be used as a treatment or cure.
63	Guideline	28	10	<p>We support this recommendation against the Lightning Process.</p> <p>In our 2020 NICE Survey on the draft guideline, a number of people have expressed disappointment that Osteopathy has been included in this section. We would like better clarification here whether the recommendation is against Osteopathy as a whole or when used in combination with life coaching, neurolinguistics programming etc.</p>
64	Guideline	28	12	<p>Remove this paragraph. This paragraph goes against earlier statements we have similar concerns as were set out in Comment 54, page 26 1.11.8</p> <p>We suggest:</p> <p><i>"Physical activity for people with M.E./CFS should only be considered if they request it and it is part of a maintenance plan for activity and energy management to support activities of daily living. It is essential that post exertional symptom exacerbation is recorded during any activity, and if progression is considered by the patient then accurate recording is needed to ensure any worsening of symptoms is identified and activity stopped."</i></p>
65	Guideline	28	1.11.18	<p>We support the below comment from Physios4ME.</p> <p><i>"We are concerned about the current level of training on ME/CFS for Physiotherapists and Occupational Therapists. Unpublished surveys by Physios for ME found ME was included in less than half of undergraduate physiotherapy courses. Many existing training programmes are based on the deconditioning model and include graded exercise therapy."</i></p>

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				<p><i>We therefore recommend changing the wording from:</i> <i>A physical activity programme, if offered, should only be delivered or overseen by a physiotherapist or occupational therapist with training and expertise in ME/CFS.</i></p> <p><i>To:</i></p> <p><i>“Any physical activity within an activity management plan should be overseen by a physiotherapist or occupational therapist who has undertaken current, evidence-based training in exercise physiology relating to ME/CFS and can evidence their continuing professional development within this speciality. An awareness of the abnormally lowered anaerobic threshold, lowered VO2 max, increased acidosis post-exercise and their implications are essential.</i></p> <p><i>Training should reflect the low to very low quality of evidence relating to GET and the additional recent evidence related to adverse physiological responses to exertion and the implications for this on activity management planning.”</i></p>
66	Guideline	28	19	<p>It is essential that people be warned about the risks of additional physical/cognitive activity and the need for accurate monitoring during any activity. It should also be noted that the act of recording symptoms is an activity in itself. We would also like to see the word ‘programme’ removed from this section as it gives the impression it is a formal exercise programme and not reflective of the small amounts of activity people should be considering.</p> <p>It should be made clear that the majority have found that physical activity programmes make their symptoms worse. The current wording suggests equal proportions for improvement, no difference and worsening when this is not the case when patient feedback is examined.</p>
67	Guideline	28-29	1.11.20	<p>We suggest removing this paragraph entirely from the guideline. It adds confusion and is open to misinterpretation. The draft guideline states that “<i>physical activity is not a curative or a treatment</i>” so it is therefore inappropriate to indicate it as a possible approach.</p>
68	Guideline	29	14	<p>People should be advised not to rush trying to return to the level of physical activity. Rather than just telling them that the time “varies”, explain that it could take several days or weeks, or even months.</p>
69	Guideline	29	18-22	<p>This section needs expanding upon as not enough information is given.</p> <ul style="list-style-type: none"> • E.g. watching TV, laying on the sofa or listening to an audio book is still a cognitive activity, yet many use this as their rest.

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				<ul style="list-style-type: none"> To rest immediately as soon as symptoms feel slightly worse than before they started an activity. Do not push through, as this will result in needing more rest later on and a worsening of symptoms for longer. Include advice on how to manage sleep disturbances, insomnia and hyper-insomnia. Sleep quality can get worse during relapses and setbacks during a flare up in symptoms. More help and support is needed than the general sleep hygiene advice. It should also be made clear that the person must listen to their body and rest when needed and not try to follow strict sleep/awake hours.
70	Guideline	30	13	This section needs personalising to the individual and the condition. For people with M.E./CFS exercise can be an inappropriate way to manage pain and comes with a potential risk of significant harm. It should be made clear that any approach to manage pain should be done with this in mind.
71	Guideline	31	5	<p>We are concerned at the recommendation not to offer any medicines or supplements to treat or cure M.E./CFS. While there is no treatment or cure, many people with M.E./CFS tell us that medicines and supplements can help their individual symptoms. We therefore request this statement be clarified. Our 2019 Big Survey found that 68% of respondents use medication for individual symptoms, 70% of whom receive them from a healthcare professional.</p> <p>In our 2020 NICE Guideline Survey, we asked respondents for their thoughts on the use of supplements/medication being referred to in the guideline. Three quarters of respondents (74%), said that they would like to see the NICE Guideline make clear that, while there is no current treatment or cure, there are approaches that can be used to help manage individual symptoms.</p> <p>The comments in Evidence Review F page 64 state that a GP should prescribe medication if in their judgement there is potential benefit in terms of symptomatic relief. This should be reflected in the recommendation.</p> <p>In our 2020 NICE Guideline Survey, we asked those who said they use medication or supplements which symptoms it was for:</p> <ul style="list-style-type: none"> 72% pain 55% sleep difficulties 25% nausea 20% Orthostatic intolerance
72	Guideline	34-35	1.11.50	In our 2020 NICE Guideline Survey we asked respondents for their views on CBT:

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			<ul style="list-style-type: none"> • 54% said they have used or would like to be offered a different type of talking therapy (eg counselling, acceptance and commitment therapy) that helps them cope with the impact of living with M.E./CFS • 46% said they have used or would like to be offered mindfulness/meditation to help them cope with the impact of living with M.E./CFS. • 41% said they have used or would like to be offered other self-help strategies to cope with the impact of living with M.E./CFS • Just 27% have used or would like to be offered CBT to help cope with the impact of living with M.E./CFS • 19% said they would not consider using any type of talking therapy or self-help strategy in this way. <p>We support the following comments made by Forward-ME:</p> <p><i>“In the evidence review at G Page 342 Line 26, the committee summarised the evidence on non-pharmacological interventions for ME/CFS. Their conclusions (from lines 40 – 44) found that: “In addition, the committee made ‘do not’ offer recommendations for CBT ...to treat or cure ME/CFS.”</i></p> <p><i>In the light of this finding, Forward-ME are mystified as to why the draft guideline discusses CBT extensively. This would appear to be discriminatory as the guideline for multiple sclerosis (MS) – a disease that has been compared to ME/CFS, at 1.5.5 states only: ‘Consider mindfulness-based training, cognitive behaviour therapy or fatigue management for treating MS-related fatigue.</i></p> <p><i>Congestive heart failure- also compared with ME/CFS only refers to Depression with reference to the NICE guideline on that topic.</i></p> <p><i>We can find no other chronic disease for which such extensive advice is given on CBT.</i></p> <p><i>We are aware that some patients may find psychological support necessary and helpful. CBT is mentioned as having two possible purposes:</i></p> <ol style="list-style-type: none"> <i>(1) Support in managing symptoms. CBT is only ever relevant when a person is behaving in a maladaptive fashion, grounded in unhelpful beliefs; therapist aims to change mind-set to their benefit in terms of changed behaviour.</i> <i>(2) CBT for support with psychological distress as far as we are aware does not exist. Person-centred supportive counselling would be fit for purpose.</i> <p><i>We are asking for this section to be re-written to state:</i></p> <p><i>‘Do not offer CBT to treat or cure ME/CFS as there is no substantive evidence that it is effective. Patients may find supportive, person-centred counselling helpful.’”</i></p> <p>It is wrong to include the statement ‘aims to improve functioning’ within the aims of CBT. This is misleading and can lead to misinterpretation. In the 2019 Action for M.E. Big Survey, of those who undertook a course of CBT:</p> <ul style="list-style-type: none"> • Only 8% said they were able to gradually increase their activity.
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				<p>This statement must be heavily caveated to ensure people are aware that for most this is not a possibility and can have a worsening effect on symptoms (13%)</p> <p>Other respondents to our 2020 NICE Guideline Survey said:</p> <p><i>“I agree that providing psychological support is very important - to deal with the impact of this condition - but my view, both as a doctor and as a patient, is that CBT is largely promoted based on cost, rather than it really being the best treatment modality. Particularly for people with a more severe disease, I think CBT can be harmful in that it applies a general technique to a vulnerable group who are often unable (physically / mentally) to engage with or benefit from this technique, not through any fault of their own (eg finding ‘evidence’ to challenge ‘negative cognitions’ eg of ‘being a burden’) may well result in more harm than good if the person is actually very disabled and cannot do much for themselves. Other psychological modalities / techniques (including mindfulness, acceptance based strategies) may be far more beneficial.”</i></p> <p><i>“I welcome the way CBT is described as helping people cope with the illness and manage symptoms - but not as a cure. I think most CBT counsellors could help provide this with some training in CFS/ME - possibly professional modules taken through online training - and think this could be explored further.”</i></p> <p><i>“I trained as a person-centred, existential counsellor and worked with people with severe/enduring mental health problems [...] CBT was a rather short-lived success, if successful at all [...] My clients would sometimes develop another mental health condition, because the original condition wasn't dealt with appropriately.”</i></p>
73	Guideline	34	7	The phrasing ‘CBT for ME/CFS’ suggests that there is an established protocol (like CBT-E for eating disorders and Trauma-Focused CBT for trauma). This is misleading.
74	Guideline	34	16	The use of ‘assume’ in this line could add ambiguity. This wording should be changed to make clear that ‘abnormal’ illness beliefs and behaviours are NOT an underlying cause of M.E./CFS.
75	Guideline	34	26	The phrase ‘work towards meaningful goals’ is open to interpretation and should be clarified to ensure no person with M.E./CFS is pressured to set a goal beyond what they feel are unmanageable. Our 2019 Big Survey showed that one in five people who undertook CBT in the last five years experienced this.
76	Guideline	35	3	<p>The Guideline recommends that CBT should:</p> <p><i>“explore their personal meaning of symptoms and illness, and how this might relate to how they manage their symptoms”.</i></p> <p>This should be removed as it gives the impression that a person with M.E./CFS can reduce their physical symptoms by changing the way they think.</p>

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77	Guideline	36	1	Additional wording is needed here to ensure that any management approach for a co-morbid condition is risk assessed against the patient's M.E./CFS. For example, any approach involving increased activity could then lead to post-exertional symptom exacerbation.
78	Guideline	37	7-8	We would like the guideline to acknowledge that for women, having their period or certain stages of the menstruation cycle can cause a flare in M.E./CFS symptoms. The common cold can cause a flare in ME symptoms so it is not always acute illness.
79	Guideline	38	5	It should be made clear here that in the case of a relapse, a person should reduce their activity levels in establishing a new energy envelope and, in some cases, stop altogether.
80	Guideline	39	2	This recommendation has been positively received in our 2020 NICE Guideline Survey.
81	Guideline	40	11	<p>We support this section. It is essential that training be given to health and social care professionals. The overriding theme in our 2020 NICE Draft Guideline Survey was that of medical education and the need for coordinated approaches to health and social care professionals to educate and inform about changes to the guideline and the risks that have been evidenced with previously agreed approaches.</p> <p>In this survey, over half of respondents (56%) are concerned that they are being advised to rely on support from professionals who have experienced/understanding of M.E./CFS – but this is not their experience. This demonstrates the need for coordinated efforts to increase understanding among the medical profession.</p> <p>We would also like a recommendation that training is given to all disciplines. One respondent to our 2020 NICE Survey said:</p> <p><i>“Many of us find that detrimental attitudes and incorrect beliefs about ME being psychological/psychosocial make it very difficult to get heard and treated for non-ME health problems as they often ascribe other symptoms to psychological causes, are patronising and sometimes insulting in their assumptions, and most seriously is a real danger of not diagnosing and treating other conditions.”</i></p> <p>It should be recognised that no amount of training or literature review by a healthcare professional could compare to the knowledge a person with M.E./CFS has about his or her own condition.</p>
82	Guideline	40	11	We would like a recommendation that a nationwide information campaign is conducted to inform health professionals about the change in guideline and require new training and assessment to ensure they are able to support people with M.E./CFS.
83	Guideline	40	12	Delete 'should'. Insert 'must'
84	Guideline	41	2	Delete 'should'. Insert 'must'.
85	Guideline	41	9	The definition of activity should include activities of daily living

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86	Guideline	43	11	<p>We would like it to make clear that those with mild M.E./CFS who are able to work often have to reduce hours in order to continue employment. Our 2020 Big Survey found that:</p> <ul style="list-style-type: none"> • Only 8% of respondents are in full time work • 90% of respondents have had to reduce their hours or stop working altogether <p>It should be noted that many people with M.E./CFS who work might have significantly reduced all non-work activities in their life in order to sustain employment.</p>
87	Equality Impact Assessment	General	General	<p>The previous equality impact assessment for this draft guideline reported that “<i>at the stakeholder workshop, the following populations were identified as having potential equality issues and should be considered within the development of the scope: older people, pregnant women, black and minority ethnic, and men. It was noted that there may be challenges for these groups to be identified and diagnosed with ME/CFS and then to access support services.</i>” The current statement states that “there was no or limited evidence identified for these groups.” This should have prompted the committee to examine reasons for this by formulating appropriate questions for literature searches and discussion. It should therefore be reflected within the recommendations for research.</p> <p>We feel that the guideline should recognise the additional difficulties faced by black, Asian and ethnic minority people in obtaining a timely diagnosis and adequate care for M.E./CFS. These difficulties were documented in Evidence review C of the draft guideline. Several papers were analysed, including de Carvalho Leite 2011; Bayliss 2014; de Silva 2013; and Hannon 2012.</p> <p>It should also be recognised that in the provided evidence, Guideline commissioned surveys and charity surveys including our 2019 Big Survey, may not be wholly representative of ethnicity. This is further evidence that an additional research recommendation is needed to focus on diagnosis, quality of life and prognosis for BAME populations.</p>

Insert extra rows as needed

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