

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

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Name of commentator person completing form:		Ingrid B. Helland		
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
				<p>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.</p>
1	Guidance	General	General	<p>The committee has produced consultation documents consisting of 2634 pages. In our opinion, the committee has done a biased review of the evidence, and a biased assessment of patient. The committee has discarded Cochrane reviews on exercise and CBT, and has suggested radical changes in recommendations compared with previous NICE guidance, without a balanced review of why. Lillebeth Larun and other colleagues at NIPH revised their Cochrane review on exercise for patients with CFS/ME based on critical comments in 2019, in dialogue with Cochrane chief editors.</p> <p>The primary studies on the different interventions are presented in tables over hundreds of pages, with</p>

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				<p>standardized assessments regarding downgrading for indirectness, risk of bias etc.</p> <p>The evidence is downgraded for indirectness when inappropriate diagnostic criteria not including PEM are used, without providing evidence to support the hypothesis that effect should be mediated by type of criteria (on the contrary there is evidence that the effect is similar across different criteria). It is strange to see how evidence from well conducted trials is reduced whereas undue weight is given to evidence from qualitative studies (even for questions on effectiveness/harm).</p>
2	Draft guideline	8	11-13	<p>We cannot see that it is justified to recommend a duration of only 6 weeks for adults and 4 weeks for children and adolescents before suspecting CFS/ME after an infection. It is not unusual that symptoms persist for more than 4-6 weeks after a serious infection. Thus this may lead to over diagnosis.</p>
3	Draft guideline	10	23	<p>CFS/ME should not be diagnosed until 6 months with symptoms, see below.</p>
4	Draft guideline	11	5-6	<p>Again, to our opinion, it is too early to diagnose CFS/ME after 3 months. Symptoms may persist for more than that after serious advents like an infection. The former recommendation of 6 months duration of symptoms is more appropriate. Action may be taken though, after 3 months, as described when CFS/ME is suspected.</p>
5	Draft guideline	17	8-	<p>Child abuse also happens in families with CFS/ME. This should be more emphasized; a CFS/ME diagnosis does not implicate that child abuse does not happen.</p>
6	Draft guideline	28	1-11	<p>One gets the impression that any kind of physical activities are harmful. It should be stressed that it is heavy physical activity programmes developed for healthy persons that are harmful, not physical activity by itself. Voluntary regular exercise promotes regulation and coherence of the body physiology and is also good for mental health. There exist (almost) no illness conditions that recommend bed rest or no exercise. However, it is important to start with gentle forms of exercise. Exercise will need to be graded up slowly – adjusted to the individual patient, otherwise it may exacerbate both fatigue and pain.</p>
7	D	53	12	<p>We cannot see that it is justified to recommend a duration of only 6 weeks for adults and 4 weeks for children and adolescents before suspecting CFS/ME after an infection. It is not unusual that symptoms persist for more than 4-6 weeks after a serious infection.</p>
8	D	53	30-32	<p>Again, to our opinion, it is too early to diagnose CFS/ME after 3 months. Symptoms may persist for more than that after serious advents like an infection. The former recommendation of 6 months duration of symptoms is more appropriate. Action may be taken though, after 3 months, as described when CFS/ME is suspected.</p>

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9	D	58	1-22	In clinical practice, psychiatric differential diagnoses are the most challenging. The list presented should include Psychiatric conditions like schizophrenia, bipolar disorders, anxiety and depression. However, it is important to recognise that all patients with longstanding illness may develop comorbid anxiety and depression – this may deteriorate course
10	D	59	1-14	We find it difficult to understand why results from studies conducted on populations not necessarily recruited with the emphasis on PEM are “ compulsory feature” . As stated earlier in this guideline, validation of diagnostic criteria is sparse. PEM is an unspecific symptom that also can be seen in patients with other diagnoses than CFS/ME, and was not considered obligatory for the diagnoses until the last decade.

Insert extra rows as needed

Checklist for submitting comments

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

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- **We do not accept comments submitted after the deadline stated for close of consultation.**

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