

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>Royal College of Physicians and Surgeons of Glasgow</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:		Dr Richard Hull, Honorary Secretary with the advice from experts in the field		
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...
Example 5	Evidence review C	57	32	There is evidence that ...

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Example 6	Methods	34	10	The inclusion criteria ...
Example 7	Algorithm	General	General	The algorithm seems to imply that ...
1	Guideline	General	General	<p>The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow has a membership of 15,000 and represents Fellows and Members throughout the United Kingdom. While NICE has a remit for England, many of the recommendations are applicable to all devolved nations including Scotland. They should be considered by the relevant Ministers of the devolved governments.</p> <p>The College recognises that ME/CFS is difficult to assess and treat. ME/CFS is a symptom complex and not a well-defined disease, with a spectrum of manifestations. The pathophysiology as the reports states is unclear. The report suggests it is a distinct entity whereas there is a clear overlap between ME/CFS, Chronic Pain Syndromes, Fibromyalgia, Psychiatric disease with physical symptoms (eg Depression) and the emerging Long COVID spectrum.</p> <p>The reviewing Committee's expertise has a clear bias to the paediatric spectrum and much of the report appears only relevant to children and young people yet covers adult years.</p> <p>The Committee does not appear to have members who have a background in rehabilitation, neurology, musculo-skeletal medicine, psychiatry (although there is a psychologist) or the chronic pain aspect of anaesthesia.</p> <p>Usually, NICE guidance relies on clear evidence of benefit from literature. Where there is no evidence or it is confused, no or few recommendations are made. While it is acknowledged that this is a difficult area, the recommendations appear aspirational rather than based on evidence. Even where the text says that evidence is mixed (for example Cognitive Behavioural Therapy), there is still strong recommendations that it should be provided and people with ME/CFS should have access to this treatment.</p> <p>It is often difficult to ascertain which recommendations are evidence based and which are not.</p> <p>NICE has developed its guidance to be evidenced based and then to use health services resources effectively. The recommendations made do not appear to be evidenced based. Many of the services are not available in many areas of the UK. There does not appear to be an economic assessment of the benefits or otherwise of the recommendations.</p> <p>There is wide literature in this area with little which is conclusive. The surrogate when the evidence base is poor will be custom and practice by acknowledged experts in the field. However, this report has not used all the</p>

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				specialities involved in management of ME/CFS and its recommendations go beyond what is expected from custom and practice. These difficulties should be discussed and acknowledged in the report.
2		8 And 42	17 14	The term fatigable has a specific neurological definition, namely decline in performance during continuous performance of a prolonged task. While this may be present in ME/CFS and other neurological disorders, the definitions given for fatigability include other examples of neurological fatigue.
3		28	6	This implies that all graded exercise therapies are based on fixed incremental increases in physical activity or exercise. In fact, most of the studies using graded exercise therapies used incremental increases which were not fixed. A more accurate description would be 'do not offer any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy <i>with fixed incremental increases</i> '.
4		37	1 and many others	The term flare is used widely in the text. Flare implies an inflammatory process which is not the case in ME/CFS. The pathophysiology of this condition is uncertain and therefore the term exacerbation is more appropriate.
5				
6				

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

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- For copyright reasons, **do not include attachments** such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.
- **We have not reviewed the evidence for the recommendations shaded in grey. Therefore, please do not submit comments relating to these recommendations as we cannot accept comments on them.**
- **We do not accept comments submitted after the deadline stated for close of consultation.**

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

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

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