

## Suspected neurological conditions

Consultation on draft guideline – deadline for comments **5.00pm** on 19 September 2017 email: [NeurologicalProblems@nice.org.uk](mailto:NeurologicalProblems@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 short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none"><li>1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.</li><li>2. Would implementation of any of the draft recommendations have significant cost implications?</li><li>3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)</li><li>4. [Insert any specific questions about the recommendations from the Developer, or delete if not needed]</li></ol> <p>See section 3.9 of <a href="#">Developing NICE guidance: how to get involved</a> for suggestions of general points to think about when commenting.</p>
<p><b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>Forward-ME</p>

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<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		None		
<b>Name of commentator person completing form:</b>		Countess of Mar		
<b>Type</b>		[office use only]		
<b>Comment number</b>	<b>Document</b> (full version, short version or the appendices)	<b>Page number</b> Or <b>'general'</b> for comments on the whole document	<b>Line number</b> Or <b>'general'</b> for comments on the whole document	<b>Comments</b>  Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.
Example 1	Full	16	45	We are concerned that this recommendation may imply that .....
Example 2	Full	16	45	Question 1: This recommendation will be a challenging change in practice because .....
Example 3	Full	16	45	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.....
1	Full and short	General	General	All references to 'ME' and/or 'CFS' as a 'functional' disorder should be removed. Rationale for this : no such 'functional' disorder exists. The UK government and related departments of government have repeatedly confirmed the official position - that these terms relate to a neurological disorder, in keeping with the

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				<p>WHO International Classification of Diseases ‘G’ code.</p> <p>The UK Government has repeatedly gone on record to the effect that ‘CFS’ and/or ‘ME’ are considered to be neurological disorder(s) of unknown origin, most recently in the House of Lords, see Hansard, 4 July 2017 Col 781 [Volume 783]. This is not new, numerous examples could be cited including written response to a Parliamentary Question in March 2013 Hansard: <a href="https://www.publications.parliament.uk/pa/cm201213/cmhansrd/chan123.pdf">https://www.publications.parliament.uk/pa/cm201213/cmhansrd/chan123.pdf</a> [page 854W; e-page 126]</p> <p>The relevant WHO ICD 10 Code is G93.3: Diseases of the nervous system (G90 – G99) Other disorders of the nervous system (G90 – G99) <b>G93 Other disorders of the brain</b> <b>G93.3 Postviral fatigue syndrome</b> Benign myalgic encephalomyelitis [Chronic fatigue syndrome is indexed to G93.3]</p> <p>Adoption of this classification is mandatory - there is a legal obligation for the Department of Health to provide ICD data to the WHO and the NHS was mandated to implement ICD-10 on 1<sup>st</sup> April 1995.</p> <p>For the avoidance of doubt, WHO ICD categories are mutually exclusive: “This is to confirm that according to the taxonomic principles governing the Tenth Revision of the World Health Organisation’s International Statistical Classification of Diseases and Related Health Problems (ICD-10) it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive.” (Personal correspondence)</p>
2	Full and short	General	General	<p>We note that this draft guideline proposes to include disorders that are of an associative/conversion/functional nature as well as <i>bona fide</i> neurological conditions. Therefore, to be legitimately mentioned in the guideline, a disorder must fall into one of these two broad categories- and it is important to be accurate as to which.</p> <p>Yet the draft mentions ME and CFS while apparently ruling out either type of neurological presentation in this regard. It is odd that the draft guideline sees fit to mention CFS or M.E. at all, given the perspective taken in respect of these terms in the draft.</p> <p>Which is, as noted above, the unsubstantiated and untenable position that these terms describe a non-neurological ‘functional’ disorder rather than a <i>bona fide</i> neurological condition given the G93.3 classification.</p>
3	Full and short	General	General	<p>The above anomaly requires to be resolved.</p> <p>In this regard, we note that G93.3 and several other G90 – 99 ‘Other Disorders of the Nervous System’ codes are not contained in the NHS schema for ‘defining neurological disorders’ that is reference 17 in the draft guideline [spreadsheet]. It is not clear what the organising principle is for inclusion and exclusion in this schema.</p>

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				<p>In the circumstances, we request that NICE make a decision as to whether to omit all references to CFS and ME from the guideline on the basis that – for whatever reason, the NHS has seen fit to exclude G93.3 from the defining neurological conditions schema [Ref 17 in the draft guideline].</p> <p>If the decision is to retain them, then these disorders must be accurately described/classified, not least because of the adverse consequences of the ensuing NHS approach to patient care that can and will flow from getting this wrong.</p>
4	Full and short	General	General	<p>We note that there has historically been confusion between CFS and ‘fatigue syndrome’ - Code F48.0 in the mental &amp; behavioural disorders section. However, as the F48 (<i>‘other neurotic disorders’</i>) codes do not appear in the ‘defining neurological conditions’ work [Ref 17 in the draft guideline] it is particularly perplexing that ‘NICE’ have still sought to take the line that the term ‘functional’ can legitimately be applied.</p> <p>It is essential that the proposed guideline should be truthful, rational, and ethical.</p>
5	Full and short	General	General	<p>We note the growing international consensus on CFS and ME, and the relatively emergence of key documents in the USA. The 2015 report of the US Chronic Fatigue Syndrome Advisory Committee, following reports from the US Institute of Medicine of the National Academies and the US National Institute for Health in that year, states that:</p> <p>“The disease is not psychiatric in nature and should not be equated with neurasthenia, somatic symptom disorder or functional somatic disorder.” [paragraph 15]</p>
6	Full and Short	General	General	<p>There is no mention of autonomic dysfunction which is common in neurological illnesses such as ‘CFS/ME’ and can be the root cause of many of the symptoms complained of.</p>
7	Full	75	Rec 31	Delete ‘other functional disorders for example, chronic fatigue syndrome and fibromyalgia’
8	Full	78	Recs 36-38	It is factually inaccurate to refer to ‘CFS; ME’ in a section on functional disorders. Please refer to general comments.
9	Full	78	Recs 36-38 line 8	re terminology: M.E. means ‘myalgic encephalomyelitis’.
10	Full	29-30	‘Related NICE’ g’lines list	Add: Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition <a href="#">NICE clinical guideline 32</a> (2006) to the list
11	Full	30	Following ‘Related NICE’ g’lines list	<p>If ‘CFS/ME’ patients are to be covered in the present guideline, add new heading ‘Guidelines presently under consideration for review’ and list:</p> <p><i>Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children</i> National Collaborating Centre for Primary Care, August 2007; NICE Guideline CG53</p>

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Insert extra rows as needed

### Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons).  
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.

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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