

## 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></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>Action for M.E.</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.		N/a		
<b>Name of commentator person completing form:</b>		Katie McMahon, Policy Officer		
<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>
				<p>Insert each comment in a new row.</p> <p>Do not paste other tables into this table, because your comments could get lost – type directly into this table.</p>
1	Full	General	General	<p>All references to 'M.E.' and/or 'CFS' as a 'functional' disorder should be removed, including statements that patients with M.E. or CFS experience functional symptoms.</p> <p>Myalgic encephalomyelitis (M.E.) and chronic fatigue syndrome (CFS) are not functional disorders. Both are indexed under G93.3 in World Health Organisation's ICD-10, under <i>Diseases of the nervous system</i>. The NHS was required to implement the ICD-10 in 1995, and as such that includes the classification of CFS/M.E. as a neurological condition. In addition, the UK Government has consistently stated that it accepts the "World Health Organization's classification of the illness as a neurological condition of unknown origin." [Lord O'Shaughnessy, Parliamentary Under-Secretary</p>

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				<p>of State Department of Health, column 781 in Hansard Volume 783, 4 July 2017]</p> <p>The assumption within this guideline that CFS/M.E. is not neurological is further concerning given that current practice is moving towards treating CFS/M.E. within services for medically unexplained symptoms (MUS). The NICE guideline for the condition makes it clear that specialist services for CFS/M.E. are likely to be needed by significant number of people with the condition [NICE CG53, 1.5.1.2, 2007]. It is likely that the approach offered by MUS services would be inappropriate in many cases. Therefore it is essential that the <i>Suspected neurological conditions</i> reflects WHO’s position that CFS/M.E. is neurological in order to provide clear guidance on the classification of the condition, as this will also impact on service commissioning and clinical practice. In so doing, the guideline would also be in line with a growing body of evidence that CFS/M.E. is neurological [Institute of Medicine, <i>Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an illness</i>, February 2015].</p> <p>Comments 2 and 3 below address two specific examples where CFS/M.E. has been stated to be, or is implied to be, a functional disorder.</p>
2	Full	14 (and 77)	18-26	<p>In the further notes relating to the referred section (which are on p78 under <i>Recommendations 36-37 – Chronic fatigue syndrome, fibromyalgia and functional neurological disorder</i>) the draft guideline states that “functional symptoms that are not primarily explained based on physical or physiological abnormalities. They are likely to have an emotional basis. They may mimic neurological disorders.”</p> <p>This statement wrongly says that patients with CFS/M.E. experience functional symptoms. The statement furthermore assumes that the symptoms experienced by CFS/M.E. patients are emotionally based, both of which directly contradict WHO’s classification of the condition as neurological.</p> <p>On the basis of this assumption the guideline states that patients “may benefit from an explanation that functional symptoms are commonly accompanied by problems with concentration and memory, and that this may reduce the overall load on clinical services.” Not only does this statement erroneously say that CFS/M.E. symptoms are functional, but translates this assumption into guidance that will result in patients being dissuaded from accessing services, which contradicts NICE’s own condition-specific guidance for CFS/M.E., CG53.</p>
3	Full	17	38-39	<p>Recommendation 72 says “Be aware that functional neurological disorder is the most common cause of minor</p>

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		(and 96-97)		<p>word-finding difficulties in adults.” In the further information for this recommendation on p96, the draft guideline additionally states that “functional symptoms that are not primarily explained based on physical or physiological abnormalities. They are likely to have an emotional basis. They may mimic neurological disorders.”</p> <p>The further information on p97 concludes that “word-finding difficulty causes undue distress in some cases, and the committee decided that a recommendation to raise awareness of functional disorder as a common cause might help GP’s reassure patients and prevent some inappropriate referrals.”</p> <p>People with CFS/M.E. experience cognitive symptoms that result in speech and language problems, including difficulty finding words [NICE CG53, 1.2.1.2, 2007]. Therefore the guideline should acknowledge that word-finding difficulties can be a result of a neurological condition, rather than its current position that the symptom is functional and may only mimic a neurological disorder.</p>
4	Full	29	28	<p><i>Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management, CG53 August 2007</i>, to be included as a related NICE guideline, as it is referred to elsewhere in the draft guideline on p78 under Recommendations 36-37.</p>
5	Full	14 (and 77)	18-26	<p>As stated in comment 1, WHO’s ICD-10 classifies CFS/M.E. as a neurological disorder; a classification that is mandated across the NHS since ICD-10’s implementation in 1995.</p> <p>In the further notes on p78, which accompany recommendations 36 and 37 on p14, the <i>Suspected neurological conditions</i> guideline states that people with CFS/M.E. should not be referred for a neurological assessment “unless the cognitive difficulties have a significant impact on everyday life.” Given that CFS/M.E. is classified within the NHS as a neurological condition, and in practice people with CFS/M.E. are treated within neurological services [Action for M.E., <i>Spotlight on specialist services</i>, 2017], the guideline ought to recognise that a referral can be appropriate without the caveat regarding a threshold of cognitive difficulties that needs to be met.</p> <p>In drawing a distinction between people whose symptoms have a significant impact on their everyday life, and people who do not meet this threshold, the guideline’s recommendation will result in inconsistent referrals for people with M.E., where those who are considered to be impacted significantly by their clinician will be referred</p>

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				while others will not receive this treatment despite each having the same condition.
6	Full	General	General	<p>CFS/M.E. also affects children, and has a significant impact on their health and wellbeing. Research has shown that the condition is the leading cause of long-term sickness absence in schools [Dowsett EG &amp; Colby J., <i>Long Term Sickness Absence due to ME.CFS in UK Schools: An Epidemiological Study with Medical and Educational Implications</i>, 1997], and children frequently tell us that the condition can leave them feeling isolated both from their peers and through the lack of awareness and understanding from professionals. Therefore it is imperative that this guideline enables clinicians and other health professionals to be aware of CFS/M.E. in children and respond appropriately.</p> <p>Comments 7-9 below address some specific areas where the draft guideline ought to acknowledge the possibility of CFS/M.E. when considering symptoms in children.</p>
7	Full	19 (and 106)	10-12	Include statement that concentration and memory difficulties are common in children with CFS/M.E.
8	Full	20 (and 115)	14-15	Include statement that postural hypertension is a common feature of CFS/M.E.
9	Full	24 (and 140)	4-5	Include statement that sleep disturbance is a common feature of CFS/M.E.

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.

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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.