

10 year surveillance (2017) – [Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\) \(2007\) NICE guideline CG53](#)

Stakeholder consultation comments form - proposal for ‘no update’

Consultation on the proposal for ‘no update’ opens on: 9am Monday, 10 July 2017

Comments on proposal to be submitted: no later than 9am Monday, 24 July 2017

Please enter the name of your registered stakeholder or respondent organisation below.	
Please use this form for submitting your comments to NICE.	
<ol style="list-style-type: none"> 1. Please put each new comment in a new row. 2. Please note – we cannot accept comments forms with attachments such as research articles, letters or leaflets. If we receive forms with attachments we will return them without reading the comments. If you resubmit the comments on a form without attachments, this must be by the consultation deadline. 3. If you wish to draw our attention to published studies, please supply the full reference. 4. NICE is unable to accept comments from non-registered organisations. If you wish your comments to be considered please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them. 	
Organisation name – Stakeholder or respondent	The Young ME Sufferers Trust
Disclosure Please disclose whether the organisation has any past or current, direct or indirect links to, or receives funding from, the tobacco industry.	None
Name of commentator:	Jane Colby

[Developing NICE guidelines: the manual](#) gives an overview of the processes used in surveillance reviews of NICE clinical guidelines.

ID	Questions	Overall response yes / no	Comments Please insert each new comment in a new row
1	Do you agree with the proposal not to update the guideline?	NO	<p>The 2007 Guideline is now 10 years old. In the intervening years much has changed with respect to biomedical knowledge of ME/CFS, in particular in the USA. As a result of these discoveries including evidence from Professor Van Ness concerning dysfunction in the aerobic/anaerobic muscle metabolism with post-exertional deterioration, the US Centre for Disease Control has taken the serious step of removing its recommendation on graded exercise from its website.</p> <p>Whilst NICE is entitled to evaluate evidence for itself, it should not withhold such information from doctors, who follow the Guideline in the belief that they are doing right by their patients, and from patients themselves, who have the right to full information on the potential benefits and risks of treatments, so as to be able to give informed consent. The Young ME Sufferers Trust [Tymes Trust] is the only UK charity dedicated to children with ME, and their parents are entitled to such full information in order to give informed consent on behalf of their children.</p> <p>To effectively censor one side of the current evidence on this disease, and the serious step taken by the CDC, is to present a partial, rather than impartial view to unsuspecting parents and their doctors – surely an unethical stance that is already reflecting poorly on NICE and its reputation. Once the medical profession learns that NICE is now, in effect, actively promoting one side of the medical debate and suppressing the other, this cannot fail to have consequences.</p>
2	Do you agree with the proposal to remove the guideline from the static list?	YES	<p>The Young ME Sufferers Trust [Tymes Trust] believes that it is essential to remove the guideline from the static list. In July 2014 a peer-reviewed paper by our Executive Director Jane Colby on 'False Allegations of Child Abuse in Cases of Childhood Myalgic Encephalomyelitis (ME)' was published</p>

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			<p>(http://www.argumentcritique.com/publications.html) (and republished with permission at http://www.tymestrust.org/pdfs/falseallegations.pdf).</p> <p>At that time there were 121 families on our list who had faced or were facing such suspicions/allegations. This number has now risen to 194, with 6 new cases in the last week. We stress that to date, not one of these families has been found guilty of anything, indicating a virtual epidemic of misunderstanding amongst medical professionals, who are diagnosing FII, MSBP and PRS, later found to be incorrect. These cases arise because the child does not recover having had CBT and GET, or because the family declines it.</p> <p>NICE now has the opportunity to highlight prominently that there is now profound medical disagreement on the efficacy and safety of its hitherto recommended treatments. If it fails in this vitally needed task, we see no abatement in the current distress and trauma suffered by innocent families and their sick children, if they are unfortunate enough to contract ME.</p>
3	Do you have any comments on areas excluded from the scope of the guideline?	YES	<p>We understand that identifying a cause for ME/CFS, or ME and CFS separately, is not the remit of NICE, although the WHO classification is neurological ICD10 G93.3. However, given that, as a consequence of NICE's treatment recommendations, children are routinely referred to mental health services rather than for further biomedical assessment and treatment such as symptom amelioration, the overall perception and widely held view amongst medical practitioners is that ME/CFS is a mental health disorder. This has resulted in the common expectation that mental health treatment will enable an apparently severely sick child to get back promptly to full time school attendance (despite the term 'chronic' being part of a CFS designation). When they are unable to, suspicions of the family like those we have already detailed above inevitably arise.</p>

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			<p>We therefore request that NICE places the WHO classification prominently, and updates its guideline to include the US interpretation of current research so as to give a properly balanced and impartial picture of the current position.</p>
4	Do you have any comments on equalities issues?	YES	<p>In 2013 Health Minister Earl Howe wrote in answer to patient group queries: “The Equality Act 2010 sets out the need to treat people equally who have a protected characteristic such as a disability.” He added: “ME/chronic fatigue syndrome (CFS) falls within the definition of disability.”</p> <p>It was most helpful that NICE accepted our recommendation and referred in its 2007 guideline to the desirability of children with ME maintaining contact with 'education' in so far as is possible, rather than 'school'. This was important because childhood ME can cause such a degree of illness and disability that it is the biggest cause of long term sickness absence from school (in staff as well as students) first revealed by Dowsett and Colby (Dowsett EG, Colby J. Long term sickness absence due to ME/CFS in UK schools Journal of Chronic Fatigue Syndrome, 1997; 3(2): 29-42). (Commentary by Dowsett http://www.tymestrust.org/pdfs/dowsettcoby.pdf)</p> <p>Nevertheless, children disabled with ME commonly suffer discrimination because doctors are uninformed regarding educational rights, and about modern educational methods (already contracted by some education authorities) that enable interactive virtual education in their homes. Being interactive, this type of education mediates against isolation and, in our experience, results not only in educational qualifications but in a substantial number of children's health improving, eventually recovering to an extent that sustainable return to school or college is achieved. A brief insertion by NICE highlighting the existence of such services would be immensely helpful.</p>

Please email this form to: surveillance@nice.org.uk

Closing date: 9am, 24 July 2017

PLEASE NOTE:

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, if NICE's reasonable opinion is that the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.