

**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](mailto:cfs@nice.org.uk)

**Please read the checklist for submitting comments at the end of this form.**

We cannot accept forms that are not filled in correctly.

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.

In addition to your comments below on our guideline documents, we would like to hear your views on these questions:

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	<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 <a href="#">Developing NICE guidance: how to get</a></p>
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	<a href="#">involved</a> for suggestions of general points to think about when commenting.
<b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):	Forward-ME
<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	<b>None</b>

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<b>Name of commentator person completing form:</b>	Countess of Mar			
<b>Type</b>	[office use only]			
<b>Comment number</b>	<b>Document</b> [guideline, evidence review A, B, C etc., methods or other (please specify which)]	<b>Page number</b> Or ' <u>general</u> ' for comments on whole document	<b>Line number</b> Or ' <u>general</u> ' for comments on 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	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 ...
Example 6	Methods	34	10	The inclusion criteria ...
Example 7	Algorithm	General	General	The algorithm seems to imply that ...

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1	Guideline	General	General	<p>Members of Forward-ME are, on the whole, extremely pleased with the tone and content of the Draft Guideline and would like to thank all those who have contributed to the development for their role in listening to the concerns of the community and for their understanding of the misconceptions faced by people with ME/CFS over many years and for coming to grips with a very difficult problem.</p> <p>We remain concerned about the use of 'chronic fatigue syndrome' (CFS) as many patients who have chronic fatigue do not have ME as is shown in section G. Our preferred term is 'ME'.</p> <p>Plausible hypotheses as to possible underlying causes have emerged from the observed pattern of illness and the wide range of physical abnormalities that have been documented for some time. This information has not yet been drawn together to produce an inclusive and conclusive picture of the reasons behind the onset and persistence of ME in each and every case. However, it is highly misleading to imply that there are not, at a minimum, some very strong clues as to what is going on.</p>
2	Guideline	1	16	We understood this would be a new guideline to <i>replace</i> guideline G53 and not an update. Please clarify.
3	Guideline	4	5	<p>Delete 'medical condition'. Insert 'disease'</p> <p>Reason: ME/CFS is a recognised neurological disease. Benign myalgic encephalomyelitis is classified by the World Health Organisation International Classification of Disease 10 (WHO ICD 10) at G93.3 (other disorders of the nervous system). The forthcoming ICD 11 maintains this classification, listing chronic fatigue syndrome there also. This classification is recognised by the Department of Health and Social Care. It is also recognised as a disease by all of the United States (US) authorities and by many researchers. It would be consistent if the term 'disease' is used throughout in place of 'medical condition' which appears to diminish the impact of ME/CFS.</p> <p>We are aware of the view that 'multi-system' is appropriate and the term 'complex' redundant. If NICE wish to retain the term 'complex' in the guideline, please clarify what this implies.</p>

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4	Guideline	4	After 15	<p>Add: It should not be confused with medically unexplained symptoms (MUS) or with functional neurological disorder (FND).</p> <p>Reason: Without these specific exclusions in the guideline, clinicians will see no need to change the current practice of misconstruing ME/CFS as MUS or FND. Other NICE materials direct them to do so and there is an urgent need for these to be updated to specifically exclude ME/CFS. For example, the Suspected Neurological Conditions Guideline NG127, in the section linking recommendations to evidence – recommendation 38 and under heading <i>Chronic fatigue syndrome, fibromyalgia and functional neurological disorder</i>, and the current Improving Access to Psychological Therapies (IAPT) manual, updated in March 2020, defines MUS with the example of chronic fatigue syndrome.</p>
5	Guideline	4	After 21	<p>Ensure that at every stage, patients must be fully informed of all the benefits and risks of procedures or treatment and that their consent is obtained. In the case of children, the parent or carer should consent.</p>
6	Guideline	5	2	<p>Delete 'should'. Insert 'must'.</p> <p>Reason: It is essential that health and social care professionals have a clear-cut understanding of ME/CFS in order to prevent harm. This requirement might incur training costs, but we are of the view that the savings in additional medical and social care costs would outweigh them in the long term.</p>
7	Guideline	5	After Line 2	<p>Insert new bullet point: a person diagnosed with ME/CFS or suspected of having ME/CFS may experience brain fog/cognitive challenges and a longer appointment time may need to be scheduled.</p> <p>Reason: executive function challenges that come under cognitive difficulties can often be both taxing and exhausting for patients during medical/social care/benefits appointments. Patients struggle to share, follow and process conversations or share and, at that time, remember historic details important to their medical outcomes, management and support.</p>
8	Guideline	5	After line 14	<p>Recognise that ME/CFS is a disability protected under the Equality Act 2010 and act accordingly.</p>
9	Guideline	5	After 8	<p>Add: Ensure that at every stage, patients must be fully informed of all the benefits and risks of procedures or treatment and that their informed consent is obtained. In the case of children, the parent or carer should consent.</p>

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				Ensure that they fulfil their legal obligations when securing informed consent. /i.e., patient made aware of any material risks involved in any recommended treatment (Montgomery vs Lanarks Health Board 2015 UK Supreme Court Judgement 11)
10	Guideline	5	12	We are particularly pleased to see this. It would maintain connection between the patient and their registered medical practitioner to the benefit of the patient and would enhance awareness of the disease to the doctor. It would also overcome the inability of patients to provide medical evidence for insurance, out of work and disability claims, and welfare benefits claims and would be likely to produce savings to the public purse if decisions are right first time.
11	Guideline	5	13	After 'changing' insert 'or the patient is housebound or has co-morbidities. In a case where a patient has both a domiciliary visit is necessary.
12	Guideline	5	After 18	It would be helpful to have a 'Management and Support Plan'. The Management part would be to manage the disease and the Support part would be for the support of the patient. Reason: Because of the fluctuating nature of ME/CFS, Forward-ME are concerned that the terms of the Management Plan may be too inflexible. It is unlikely in the near future that there will be a 'specialist team' as envisaged by the guideline, to prepare a plan with the patient.
13	Guideline	5	19	The whole of this section is very welcome. A proper understanding of ME/CFS should result in reduced administration and litigation costs to the NHS and local authorities.
14	Guideline	6	7	This section is also most welcome as it should help health and social care professionals to understand the more severe manifestations of the disease. It makes clear to hospital staff the particular needs of the severely affected should they need admission to hospital. While it is not the primary purpose of the guideline, it should also help DWP officials and healthcare professionals employed by the disability assessing agencies to gain enhanced understanding which could result in cost savings for benefit reviews and appeals if decisions are correct in the first instance.
15	Guideline	5		
16	Guideline	7	4	Delete 'may'. Insert 'are likely to'.

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17	Guideline	8	After line 9	Add bullet point: 'Be aware that misdiagnosis is relatively common and cases of serious but treatable diseases are missed.' There need to be more detailed differential diagnoses in this section.
18	Guideline	8	9	It would be helpful if this point could be expanded to clarify appropriate baseline investigations as it was in the 2007 NICE Guideline CG53. It would be even more helpful to have a further section on specialist investigations relevant to ME/CFS. Unless and until patients are investigated the risk of a 'nothing physically wrong, label sticking like glue remains.
19	Guideline	9	Box above Line 1	First line of bullet point: after 'problems' insert 'processing' Third line of bullet point: Delete 'confusion'. Insert 'uncertainty' Reason: Confusion may be interpreted as a lack of mental capacity
20	Guideline	9	4	As there is no specific NICE guidance for orthostatic intolerance to refer on to, the content here is insufficient. Be aware of postural tachycardia syndrome (PoTS), neurally mediated hypotension and orthostatic hypotension. Patients should be referred to a specialist with an interest in orthostatic intolerance. Consider providing compression hosiery and increasing salt and fluid intake whilst awaiting specialist input.
21	Guideline	9	After line 6	Add: Bullet point 'dysautonomia'.
22	Guideline	11	7	After 'management' insert 'and support'
23	Guideline	11	7-8	We remain concerned that there is a dearth of consultant specialists in this field. As there is, currently, no effective treatment we consider that general practitioners (GPs) should take responsibility for their patients with ME/CFS. We would encourage specialist doctors and nurses to train within each GP practise. Approved distance-learning programmes are already available. Patients should be offered specialist consultant referrals if they choose.
24	Guideline	11	8	After 'management' insert 'and support'. It would be helpful to have a Management and Support Plan. The Management part would be to manage the disease and the Support part would be to support the patient.
25	Guideline	11	9	In view of the current shortage of specialist ME/CFS paediatric specialist teams, and as diagnosis can be made on the clinical history, advice sometimes may be sought from a specialist ME/CFS paediatrician remotely after the GP has done the basic investigations to exclude other conditions.

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26	Guideline	12	10	After 'management' insert 'and support' and carry through the implications for the proposals currently set out in section 1.5.2 - 1.5.4 and developed in late sections of the draft.
27	Guideline	14	16	Delete 'medical condition'. Insert 'disease'
28	Guideline	14	18	At the end insert: 'and are worsened by exertion'
29	Guideline	15	10	Delete 'condition'. Insert 'disease'
30	Guideline	16	6 - 11	Replace 2 paragraphs with the following: 1.7.1 Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect.  1.7.2 Safeguarding assessments in people with confirmed or suspected ME/CFS, if needed, should be carried out and overseen by health and social care professionals who have training and experience in ME/CFS.
31	Guideline	16	After Line 16	Be aware that ME/CFS in children should not be mistaken for very rare conditions such as Munchausen's syndrome by proxy or with fabricated or induced illness
32	Guideline	18	After line 18	Insert new bullet point: 'they may have prepared prior to an arranged appointment by remaining completely inactive for some time'
33	Guideline	19	1	Add: 'take into account 1.1.8 and discuss .....
34	Guideline	19	17	After 'management' add 'and support'
35	Guideline	21	5	At end add: 'full or part time. Return to these activities is likely to be gradual, if possible at all. Pushing to continue to work or attend school or further education is likely to result in lasting illness and disability.'
36	Guideline	23	4	At end add: 'if and when able'
37	Guideline	23	9	After 'management' add 'and support'.
38	Guideline	31	After 14	Insert new bullet point: 'avoid giving a further drug to counter side effects.'
39	Guideline	34 and 35	Whole pages	In the evidence review at G Page 342 Line 26, the committee summarised the evidence on non-pharmacological interventions for ME/CFS. Their conclusions (from lines 40 – 44) found that: "In addition, the committee made <b>'do not' offer</b> recommendations for CBT .....to treat or cure ME/CFS." In the light of this finding, Forward-ME are mystified as to why the draft guideline discusses CBT extensively.

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				<p>This would appear to be discriminatory as the guideline for multiple sclerosis (MS) – a disease that has been compared to ME/CFS, at 1.5.5 states only: ‘Consider mindfulness-based training, cognitive behaviour therapy or fatigue management for treating MS-related fatigue.</p> <p>Congestive heart failure- also compared with ME/CFS only makes reference to Depression with reference to the NICE guideline on that topic.</p> <p>We can find no other chronic disease for which such extensive advice is given on CBT.</p> <p>We are aware that some patients may find psychological support necessary and helpful. CBT is mentioned as having two possible purposes:</p> <ol style="list-style-type: none"> <li>(1) Support in managing symptoms. CBT is only ever relevant when a person is behaving in a maladaptive fashion, grounded in unhelpful beliefs; therapist aims to change mindset to their benefit in terms of changed behaviour.</li> <li>(2) CBT for support with psychological distress as far as we are aware does not exist. Person-centred supportive counselling would be fit for purpose.</li> </ol> <p>We are asking for this section to be re-written to state:</p> <p>‘Do not offer CBT to treat or cure ME/CFS as there is no substantive evidence that it is effective. Patients may find supportive, person-centred counselling helpful.’</p>
40	Guideline	37	1 - 24	Forward-ME are very pleased to see these two sections so clearly expressed
41	Guideline	40	12	Delete ‘should’. Insert ‘must’
42	Guideline	41	2	Delete ‘should’. Insert ‘must’.
43	Guideline	43	3 - 8	We hope that this definition will be expanded to include management (of the illness) and support (of the patient) as per comment 21. We are extremely concerned that any such plan should not always and automatically form the basis for all other assessment plans.

Insert extra rows as needed

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### 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.**
- **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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