

**National Institute for Health and Care Excellence**


**Proposed Static List Clinical Guidelines**

**Stakeholder Comments**

**Please enter the name of your registered stakeholder organisation below.**

NICE is unable to accept comments from non-registered organisation or individuals. If you wish your comments to be considered please register via the [NICE website](#) or contact the registered stakeholder organisation ([links to stakeholder lists are at the bottom of this document](#)) that most closely represents your interests and pass your comments to them.

<b>Stakeholder organisation:</b>		<b>FORWARD-ME</b> (New application)	
<b>Name of commentator:</b>		<b>Countess of Mar</b>	
<b>Comment No.</b>	<b>Guideline title and number comment relates to, e.g. CG29 dental recall</b>	<b>Agree / Disagree with proposal to put on the static list</b>	<b>Comments</b>
			Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table
Example	CG29 – Dental recall	Disagree	Our comments are as follows .....
Proformas that are not correctly submitted as detailed in the line above may be returned to you			

1	CG53	Disagree	<p>We are writing to you as members of the Forward ME Group – an alliance of national patient support and research funding organisations for people with ME and CFS .</p> <p>At our meeting on Tuesday 15 October at the House of Lords we discussed a proposal to place the NICE Guideline on CFS/ME (CG53) into the static list. We express our extreme concern over this proposal and strongly feel that the guideline must remain on the active list for the following reasons.</p> <p>Medical and scientific advances in relation to ME and CFS are taking place very rapidly. We therefore believe this is completely the wrong time to remove this guideline from the active list when these developments need to be regularly reviewed.</p> <p>When Professor Peter Littlejohns attended the meeting of the All Party Parliamentary Group on ME in February 2007 it is minuted that:</p> <p>“He explained that he had been responsible for clinical guidelines at NICE since their inception. All NICE guidelines were produced on the basis of best available evidence and on a process based on transparency, active consultation and review. He added that guidance however robust is not set in stone; medical advances can happen very quickly and NICE aims to make guidance as up to date as possible. A total of 118 guidelines, including 51 of clinical guidance, have been produced over the past 18 months. NICE was the biggest guideline production unit in the world. Any organization affected by a guidance should be part of the development of that guideline.” (None of which has ever materialised).</p> <p>Individual members of the Forward ME Group who are also stakeholders will be sending submissions which will cover our concerns in more detail. However, as a united group representing people with ME and CFS in the United Kingdom, we feel so strongly about this proposal that we are sending in this joint response.</p> <p>Yours sincerely</p>  <p>Countess of Mar, Chairman Forward-ME on behalf of:  Tanya Harrison, BRAME  Janice Kent, ReMEember  Charles Shepherd, ME Association  Sonya Chowdhury, Action for ME  Jane Colby, Tymes Trust  Sue Waddell, ME Research UK  Hannah Clifton, ME Trust  Mary-Jane Willows, Association for Young People with ME  Anne Faulkner, Chronic Fatigue Research Foundation  Arlene Wilkie, Neurological Alliance.</p>
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**Please email this form to: [staticlist@nice.org.uk](mailto:staticlist@nice.org.uk)**

**Closing date: 5pm on 23<sup>rd</sup> October**

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Registered Stakeholder Lists:

1. [A model of service provision for pregnant women with complex social factors \(CG110\)](#)
2. [Acutely ill patients in hospital \(CG50\)](#)
3. [Antenatal care \(CG62\)](#)
4. [Antisocial personality disorder \(CG77\)](#)
5. [Barrett's oesophagus – ablative therapy \(CG106\)](#)
6. [CFS/ME \(CG53\)](#)
7. [Colonoscopic surveillance \(CG118\)](#)
8. [Common mental health disorders \(CG123\)](#)
9. [Critical illness rehabilitation \(CG83\)](#)
10. [Dental recall \(CG19\)](#)
11. [Diarrhoea & vomiting in children under 5 \(CG84\)](#)
12. [Donor breast milk \(CG93\)](#)
13. [Drug misuse – opioid detoxification \(CG52\)](#)
14. [Faecal incontinence \(CG49\)](#)
15. [Food allergy \(CG116\)](#)
16. [Metastatic malignant disease of unknown origin \(CG104\)](#)
17. [Metastatic spinal cord compression \(CG75\)](#)
18. [Neutropenic sepsis: prevention and management in cancer patients \(CG151\)](#)
19. [OCD & BDD \(CG31\)](#)
20. [Prophylaxis against infective endocarditis \(CG64\)](#)
21. [PTSD \(CG26\)](#)
22. [Respiratory tract infections \(CG69\)](#)
23. [Sedation in children \(CG112\)](#)
24. [Self-harm \(CG16\)](#)
25. [Surgical management of OME \(CG60\)](#)
26. [Urinary incontinence in neurological disease: management of lower urinary tract dysfunction in neurological disease \(CG148\)](#)
27. [When to suspect child maltreatment \(CG89\)](#)

