

National Institute for Health and Care Excellence

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management

Roundtable discussion - Minutes

18 October 2021

Thames Room, 2nd Floor 2 Redman Place, London, E20 1JQ

Chair:

Professor Dame Carol Black

External attendees:

25% M.E. Group	Helen Brownlie
Academy of Medical Royal Colleges	Helen Stokes-Lampard
Action for ME	David Strain
British Association for CFS/ME	Vikki McKeever
Chartered Society of Physiotherapy	Matthew Liston
Forward-M.E.	Simon Chandlers
#ME Action	Janet Sylvester
The ME Association	Charles Shepherd
ME Research UK	Jonathan Davies
The ME Trust	Helen Winning
NHS England & NHS Improvement	Celia Ingham-Clark
Rehabilitation Medicine Specialist	Lynne Turner-Stokes
Royal College of General Practitioners	Martin Marshall
Royal College of Occupational Therapists	Sue Pemberton
Royal College of Paediatrics and Child Health	Nick Bishop
Royal College of Physicians	Andrew Goddard
Royal College of Psychiatrists	Adrian James
Science for ME	Jonathan Edwards
Tymes Trust	Nigel Speight

NICE & Guideline developer attendees:

Gillian Leng	Chief Executive
Paul Chrisp	Director, Centre for Guidelines
Christine Carson	Programme Director, Centre for Guidelines
Peter Barry	ME/CFS Guideline Chair
Ilora Finlay	ME/CFS Guideline Vice Chair
Kate Kelley	Developer Guideline Lead
Toni Tan	Technical Adviser
Rupert Franklin	Senior Guideline Commissioning Manager
Rebecca Smith	Associate Director External Communications
Helen Finn	Senior Communications Manager
Philip Ranson	Media Relations Manager

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Agenda Item	Minutes
1	<p>Welcome</p> <p>Dame Carol welcomed everyone to the roundtable and stated the aims and objectives of the meeting as follows:</p> <ul style="list-style-type: none"> • To set out the approach that NICE takes to developing guidelines. • To set out the key elements of the ME/CFS guideline and the rationale for the recommendations that have been made. • To discuss the concerns that have been raised about the guideline. <p>The chair asked everyone to observe the following principles during the meeting:</p> <ul style="list-style-type: none"> • The importance of mutual respect and a compassionate discussion – acknowledging that all attendees want to see a guideline published which will ensure people with ME/CFS get the best possible care. • Not recording the meeting or sharing details about the discussion on social media during the meeting. • Following the Chatham House Rule. That is, that after the meeting people are free to talk about what was discussed but not to disclose who made any particular comment. • Keeping contributions brief to facilitate discussion.
2	<p>Principles of guideline development</p> <p>Paul Chrisp also welcomed everyone to the meeting and thanked all attendees for giving their time.</p> <p>Paul presented a high-level overview of NICE’s guideline development process (see slide set).</p> <p>There was a question as to whether NICE had done anything differently in developing the ME/CFS guideline. Paul confirmed that this guideline had been developed in line with NICE’s published methods and processes.</p>
3	<p>Guideline summary</p> <p>Peter Barry presented a summary of how guideline development proceeded (see slide set)</p> <p>Dame Carol opened the meeting up for discussion. In response to questions, NICE clarified that:</p> <ul style="list-style-type: none"> • the focus groups for children and young people were 1:1 sessions.

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	<ul style="list-style-type: none"> • The recommendations were not decided on by voting, they were reached by consensus. Reaching consensus was a careful and iterative process. • The whole guideline was agreed by the committee, including the recommendations on graded exercise therapy (GET) before there were resignations. • During development, the limitations of the evidence base for children and young people were acknowledged.
4	<p>Diagnosis</p> <p>Peter Barry presented the committee’s approach to the recommendations on diagnosis (see slide set).</p> <p>Dame Carol opened the meeting up for discussion.</p> <p>The group discussed the place of post exertional malaise (PEM) in diagnosis and the implications of this for consideration of the evidence. The committee identified the features that are common to all or most of the criteria. They also considered the usability of the criteria as a clinical tool and the balance between over- and under-diagnosis. The Institute of Medicine (IOM) 2015 criteria were judged to provide a good balance. It was explained that PEM is included as a defining symptom in the IOM criteria.</p> <p>NICE clarified that therefore, some studies were downgraded for indirectness, but they were not excluded. These studies were also found to be low quality evidence for other reasons than indirectness, and a reanalysis of the studies based on a requirement of 95% of the population having PEM rather than 100% did not impact on the quality assessment.</p> <p>It was not felt that any clarification or additional information is needed in relation to diagnosis.</p>
5	<p>Graded Exercise Therapy</p> <p>Peter Barry presented the committee’s approach to the recommendations on graded exercise therapy (GET) (see slide set).</p> <p>He clarified that the definition of GET used in the guideline is that set out in the trials, including the PACE trial.</p> <p>Dame Carol opened the meeting up for discussion.</p> <p>There was conversation about the definition of GET, how it is delivered in practice and the fact that the term GET is understood to have different meanings by different people and that it has become a highly contested term. There was agreement that personalised exercise plans have a place for people with ME/CFS that want to undertake them.</p>

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	<p>The group discussed the potential impact of the guideline on commissioning and delivery of services. There was acknowledgment that delivery of individualised plans can take time.</p> <p>There was discussion around the meaning of specialist teams and services for ME/CFS.</p> <p>The group talked about the importance of listening to patients and their families about harms, especially considering the Cumberlege review.</p> <p>Some attendees felt that GET, as defined in the guideline, is not what is delivered in practice. Conversely, others disagreed and reported that they still see people who have had GET, as defined in the guideline, with fixed incremental increases and this has caused significant harm in people with PEM.</p> <p>NICE indicated that it would consider further clarification of the definition of GET as used in the guideline, so it is clear what is, and is not, being recommended so that appropriate services are delivered. NICE will also look at the recommendations on specialist teams with a view to improving clarity.</p>
	<p>Break</p>
<p>6</p>	<p>Children and young people</p> <p>Peter Barry presented the committee’s approach to the recommendations for children and young people (see slide set).</p> <p>Dame Carol opened the meeting up for discussion.</p> <p>The round table discussed the importance of ensuring children and young people, especially those with severe ME/CFS, are safe through regular review and appropriate interventions.</p> <p>NICE pointed to the recommendations on frequency of review that are already contained in the guideline and will consider the positioning of these recommendations to improve clarity and understanding.</p>
<p>7</p>	<p>Cognitive Behavioural Therapy</p> <p>Peter Barry presented the committee’s approach to the recommendations on cognitive behavioural therapy (CBT) (see slide set).</p> <p>Dame Carol opened the meeting up for discussion.</p> <p>In the main, what is being delivered matches what the guideline recommends.</p> <p>The roundtable discussed the positioning of CBT as ‘not curative’ or as a ‘treatment’ with concerns that this may have a negative impact on commissioning of services.</p>

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	<p>NICE explained that the wording in the guideline reflects the change in emphasis of the recommendations on CBT. That is, it may be beneficial for symptom relief rather than as a cure for ME/CFS, and that it helped people to have realistic expectations. It was explained that this was felt to be a particular issue with this condition.</p> <p>NICE will consider further explanation on this point to support commissioning of services.</p>
8	<p>Next Steps</p> <ul style="list-style-type: none"> • NICE’s guidance executive will reflect on the discussion in its meeting on 19 October 2021 and will update attendees and stakeholders shortly afterwards.
9	<p>Summary of discussion and any other business</p> <p>Gillian Leng thanked everyone for a very helpful and productive discussion and added the following summary:</p> <ul style="list-style-type: none"> • Clear that issues around commissioning of services needs to be addressed. • Training materials could help with implementation. • Examples of good practice from the patient perspective would be a positive step. • NICE will work with system partners and stakeholders on these. <p>Paul Chrisp also thanked everyone for their time and added his key points:</p> <ul style="list-style-type: none"> • There is more agreement than disagreement. • Work to amplify areas of agreement and aid understanding through greater clarity or additional narrative. • Consider a joint statement from the attendees. <p>Dame Carol added her thanks for a positive discussion and drew the meeting to a close.</p>