

**CHRONIC FATIGUE SYNDROME / MYALGIC ENCEPHALOMYELITIS
(CFS/ME) GUIDELINE**

Stakeholder Comments

Please use this form for submitting your comments to the Institute - cfs@nice.org.uk

1. Please put each new comment in a new row.
2. Please do not paste other tables into this table, as your comments could get lost – type directly into this table.
3. Please fill in the document you are commenting on in the first column, for example, the **Full version**, or the **NICE version**.
4. Please insert the **Page number (given at the bottom of the page)** in the 2nd column and the **Line Number** (given at the far left of the document). If your comment relates to the document as a whole, please put **'general'** in this column. **Please refer page numbers not section numbers.**

Name:		Dr Jill Moss DUniv [Open]	
Organisation:		Association of Young People with ME (AYME)	
Document.	Page Number	Line Number	Comments
Indicate if you are referring to the Full version , or the NICE version .	Indicate Page number or 'general' if your comment relates to the whole document	Indicate Line number	
FULL VERSION	General		<p>Please insert each new comment in a new row.</p> <p>On a first scan read – the view that a busy clinician will have – the draft Full Version Guideline is rather disappointing. It's length and complexity risks the busy practitioner looking only at the first piece of Management: 'Priority Recommendations' at the bottom of page 21.</p> <p>AYME believes the GDG wants to offer the patient choice, and to show supportive and open collaboration with their clinician as shown on page 86, 4.3.6.3, but much of the wording elsewhere is very prescriptive and is at odds with patient choice. The first recommendation at the bottom of page 21 gives the impression there is no need to look further than CBT or GET for treatment options.</p> <p>Terminology - Activity Management The term 'Activity Management' as a management approach in its own right is relatively new, even though its principle is used in all the management approaches. We are all aware that the terms CBT and GET are very unpopular amongst the CFS/ME community and if faced with them patients will often turn away instantly.</p>

			<p>Historically CBT and GET were often administered most inappropriately, with patients encouraged to exercise well beyond their limits, causing severe relapses, especially in the severely affected. The fact that both CBT and GET, when delivered by a trained therapist, involve carefully graded <i>activity management</i> needs to be flagged up very early and loudly.</p>
	Page 26	Bottom, dark blue box	<p>When one is referring to Activity Management as a treatment approach in its own right, it needs capitals. Therefore page 26 bottom, dark blue box must have capitals on Activity Management.</p>
	General		<p>Whilst AYME understands that evidence-based management approaches such as CBT and GET must obviously be included in a NICE document, we are concerned that other, less structured approaches, such as 'Activity Management', do not lend themselves to rigorous research, and have therefore been sidelined somewhat in research terms. Gentler approaches, away from Graded Exercise, are popular with children and young people because they allow more opportunity for vital social and educational activities. They also suit the severely affected as they are much more individual and are very patient-centred, which is most necessary for this very ill group. There is undoubtedly some excellent CBT programmes in existence for mildly and moderately affected patients, but there is a risk that 'old style' CBT therapists will continue with outdated views if it's not clearly explained that <i>careful, paced</i> increase in <i>activity</i> levels, is the way forward. In either case, most of our very severely affected members have found these programmes to be totally unsuitable for their needs. AYME has young members who are so severely affected they are tube-fed, and who can faint if they raise their head from the pillow for more than a few seconds. The draft Guidelines does not address this very severe end of the illness spectrum, yet this is the most challenging form of CFS/ME and is where professionals need most information, guidance and support, as they will come across it so infrequently.</p> <p>AYME would like to see the term 'Activity Management' used as a recognised management programme much more in the document to show that the NICE Guidelines are new and have moved on from the recommendations in the CMO's report in 2002. We feel this would show that NICE recognises the very severe end of the illness, and the need to make increases in activity at the severe patient's presenting level of ability, rather than applying a 'one size fits all' approach. It is so important for clinicians to recognise that in the very severely affected, the increases might need to be infinitesimally small at the beginning of the programme. To use 'Activity Management' as a term, will have moved the NICE Guidelines on from the foundation of the CMO's report, and, with the use of percentage increases in activity, be</p>

			<p>more adaptable for the whole range of functional ability, not just the mildly and moderately affected.</p> <p>Child Protection Child protection issues are still, unfortunately, a reality for some families whose children are very severely affected by CFS/ME. This situation could be helped greatly if these guidelines were to better describe the symptoms of and management techniques for very severe CFS/ME and the fact that it can affect children, not just adults, this badly. It is doubly important for clinicians to have information about the severe form of the syndrome in young children, as this helps prevent child protection concerns becoming an issue for the medical team, the family, and for Social Services. It would save a lot of pain, anger and resentment, not to mention public time and money in the unnecessary investigation and legal prosecution of cases, which to date have all been resolved as unfounded. We feel that sadly, the current draft does nothing to move the plight of these most difficult cases forward, and we would urge the GDG to address this issue specifically, to help prevent future CFS/ME families with very severely affected children experience the same unnecessary problems.</p> <p>Anecdotal evidence AYME would like the dearth of research evidence for the severely affected to be flagged up earlier and louder. We would also hope that more attention is given to the anecdotal evidence of Activity Management. The evidence-based research on management is often restricted entirely to CBT and/or GET, which will bias management proposals if anecdotal evidence isn't included. It should be explained that research studies on CBT and GET only involve patients who are physically able to attend research clinics, meaning that few, if any, include the severely affected and/or children. In addition, the population studies are small. In the absence of research on the popular Activity Management, one must take notice of anecdotal evidence from patients, or at least offer a more generalised first recommendation (see below).</p>
FULL VERSION	Page 21	Line 20	<p><i>'CBT and GET should be the first choice of therapies'</i> This prescriptive statement does not sit with the rest the recommendations on page 22.</p> <p>If the 'Main Recommendations' could begin with a more generalised statement – as below, AYME feels that the excellent recommendations which follow on page 22 will then be read thoroughly, and maybe the entire Guideline given a fair study.</p> <p>AYME suggests that the Guidelines begin with one, overriding recommendation (see below) to replace Page 21 Line 20:</p> <ul style="list-style-type: none"> • In order for a child or adult to return to normal

			<p>activity, evidence-based research indicates that CBT and GET – when carried out in a flexible, collaborative dialogue with patients by therapists with relevant training and experience – have some success for those mildly or moderately affected with CFS/ME. However, as there is a dearth of research in the severely affected patient and children, management of these patients in particular should be based on establishing a cautious and controlled, rehabilitative approach, ensuring that a solid and sustainable baseline is maintained in the first instance before cautiously increasing activity slowly and carefully within the patient’s functional capacity.</p>
Full Version	Page 22	Line 6 Line 12 Line 14	<p>The following recommendations are very good, particularly: patients given information on a range of therapies consider patient preference patients given information on support groups</p>
	Page 78	4.1	Recommendation – very good
Full Version	Page 138	Line 5&6	<p>Inconsistencies: <i>‘...GDG considered that patients should take the lead on any behavioral approaches to manage their CFS/ME’</i> is excellent ... but Page 21 line 20 (above) as it stands, contradicts this statement.</p>
	P106		<p>Children and Young People AYME recognises that CFS/ME is the same illness for children and adults. However, the impact of the illness is very different for children and this has not been sufficiently addressed. More reference needs to be made to the NSF ‘ME exemplar’ and to the RCPCH Guidance 2004, particularly with reference to the very small child needing constant vigilance (Pg 38 3.1.3 RCPCH) and the general relationship with the family (page 43 management of CFS/ME RCPCH 2004).</p> <p>In addition, diagnosis of children and young people could be enhanced by referencing the RCPCH Guidance on P106.</p>
	Pg 24	Line 6	<p>Ongoing medical support. Many patients are diagnosed and then forgotten in an ‘out of sight, out of mind’ scenario. It is vital that clinicians are aware of the need for ongoing medical support following diagnosis. An additional recommendation is suggested for Pg 24 Ln 6</p> <ul style="list-style-type: none"> • Once a diagnosis has been made it is important that the medical team makes arrangements for continued and regular support, which may mean domiciliary visits for severe and very severely affected patients.

	Pg 258	7.3	clinician '. For all severely affected people, but children in particular, we would wish for this recommendation to be added under 7.3 Page 258.
Full version	55: Patient's experiences	Section 3	<p>The excellent Patients' Experience section should be enlarged to include personal stories from health workers and educationalist (and parents?). AYME has several excellent, succinct articles which have been published in the parent newsletter LINK and available on our web-site www.ayme.org.uk</p> <p>Section 3 is excellent. It points out that patients wish to follow an Activity Management approach and not a Graded Exercise programme. AYME would like to see the Guidelines showing a collaborative approach with the printed patients' experience and recommend Activity Management.</p>
Full version	Page 139	9-18	<p>Goals</p> <p>One cannot be prescriptive in CFS/ME. The Goal in Line 11: <i>'30 mins of moderate aerobic exercise, 5 days out of 7 (for example a brisk walk)</i> is of no practical value. After all - how many <u>healthy</u> people take a brisk 30 mins walk 5 days out of 7? This is only a realistic long-term or 'ultimate' goal for a mildly affected person with ME and then only if it was achievable prior to the onset of the illness.</p> <p>AYME believes that clarification is needed between the 'Ultimate Goals', allowing short-, medium- and long-term goals' to be placed in between. This would ensure a more gentle and carefully graded approach, particularly for the very severely affected.</p> <p>Percentages are less prescriptive and more patient-centred</p> <p>All people with CFS/ME, but particularly those who are severely and very severely affected, need to be taught that their activity management must start from a realistic baseline in order to achieve success. A more generalised statement is needed on page 139, with specific examples, but using percentage ratings rather than specific time goals.</p> <p>AYME suggests that somewhere on Page 139 it should be pointed out that:</p> <ul style="list-style-type: none"> • All goals must be achievable. Clinical trials of GET have been based on an ultimate goal of achieving and maintaining 30 minutes of aerobic exercise. However, this stated goal may be completely inappropriate for many patients, especially those severely or very severely affected, who may be bed-bound, unable to weight bear. A sustainable baseline should be built up gradually by increases of 10%-15% for each activity using short-term goals (eg for the very severely affected - Step 1: propped upright for 60 seconds three times a day for one week;

			Step 2: propped upright for 70 seconds three times a day for one week, and so on).
Full Version	Page 26	box top left	Please add: Under activity management: that a <ul style="list-style-type: none"> • “...baseline of activity is maintained in the early stages, and then increments must be very small (10%-15%) and achievable”.
Full version	Pg 261	Ln 26	Please add <ul style="list-style-type: none"> • ‘short stay in an appropriate hospital environment
Full version	Pg 261	Ln 11	Please change <ul style="list-style-type: none"> • ‘need to be’ ...to ...’must be’
Full version	Pg 264	Ln 26	Please add <ul style="list-style-type: none"> • ‘... on a 3-6 month cyclical programme’
Full version	Pg 87 Pg 192 Pg 195 Pg 258	Ln 9 6.3.6.21 6.3.6.26 7.3.1.3	Please add <ul style="list-style-type: none"> • Telephone and email together when ‘support’ is mentioned
Full version	Pg 141 Pg 197	19-21 6.3.6.30	Sleep This section is too brief and needs a reference to the excellent document on sleep found at cfspod.net/Document%20files/Bristol/Sleep.doc Please add that <ul style="list-style-type: none"> • ‘one should move waking times back slowly, by 15/30 mins a week as part of a sleep hygiene plan’.
Full version	Pg 142	Ln 4	Please add <ul style="list-style-type: none"> • ‘...important for the patient to have an agreed written plan’
Full version	Pg 190	6.3.6.18	Please add <ul style="list-style-type: none"> • ‘... should be reviewed with their clinician and reduced
Full version	Pg 188	6.3.6.14	Please add: <ul style="list-style-type: none"> • ...gradual increases.
Full version	Pg 199	6.3.6.37	Following the diagnosis of a viral illness as a set-back it should be recognised that rest is needed whilst the virus is active. The CFS/ME management plan should be returned to, once the virus has cleared.

Please add extra rows as needed