

25% ME GROUP
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Sir Andrew Dillon
Chief Executive
National Institute for Health and Care Excellence
10 Spring Gardens
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RE: ME/CFS Clinical Guidelines

Dear Members of NICE committee,

We, the 25% ME group, would like to make our voices heard with regard to the use of Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) for patients with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS).

Our members are those with the worst forms of the illness, those who suffer the most severe symptoms, and whose voices should be listened to the most attentively, because it costs them so dearly to speak. This illness is frequently conflated so that observations on one group of patients are applied to another without regard as to whether this is appropriate. Our members are people who have suffered deterioration and damage as a result of this cavalier attitude, and who would like the NICE committee to carefully consider the likely outcomes of not listening to our experiences and trying to understand our point of view.

Our 700 members are almost all housebound because of the illness. Many are bed-based, meaning their lives are spent mainly in bed, and a large number are bedbound. Many of us have been at this level of illness for decades, and the future is bleak because the chances of us recovering seem remote, whereas the likelihood of relapse is an ever-present sword over our heads, which we spend every hour of every day trying to ameliorate.

Doctors on the whole are not aware of us; we do not ask for much from them, and we appreciate that home visits are costly and time-consuming. We cannot get to surgeries and appointments, so we become invisible. Most of us, despite being incapacitated by a serious chronic illness, do not see any medical professional from one year to the next – no annual check-ups, nobody takes our blood-pressure or listens to our hearts, nobody asks how we are affected by the levels of pain and suffering that we experience on a daily basis. Our lives are not documented, so trainee doctors do not learn about us. When we come into contact with a medical professional we are as likely to meet scorn and abuse as we are to receive any form of compassion or understanding of our plight. Our illness is constantly demeaned by referring to it as 'chronic fatigue', which is like defining a Parkinson's patient as having 'chronic shaking'.

Since the 25% Group was formed in 1993, we have repeatedly written to health ministers, doctors, the Secretary of State, Royal Colleges and medical journals. Our letters have taken many hours of our time and have been written through physical pain and 'brain fog' a serious symptom which makes thinking, including word retrieval, extremely difficult.

Our main requests have always, since our inception, been the same:

- Research into the biological aspects of the illness.
- Recognition of the severity of the illness.
- Support for patients in order for them to have the best quality of life possible.
- Removal of GET and CBT from the guidelines for doctors (NICE guidelines).
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It is this final point that we are writing to you about today.

Graded exercise is a fine concept for healthy people; and for all we know it might be helpful for other chronic conditions. Certainly, it is useful for recovering from broken bones or injured muscles. Doctors by themselves cannot be expected to understand the complex nature of this condition, and generally do not have the time nor the inclination to research the journals and extensive internet discussions in order to follow the reasons for their patients' distress.

There is something about ME which makes patients intolerant to 'exercise', which was clearly described by Melvin Ramsey in 1955:

“Once the syndrome is fully established the patient presents a multiplicity of symptoms which can most conveniently be described as follows.

1. Muscle phenomena

- [Fatiguability]: Muscle fatigability, whereby, even after a minor degree of physical effort, three, four or five days, or longer, elapse before full muscle power is restored and constitutes the sheet anchor of diagnosis. Without it I would be unwilling to diagnose a patient as suffering from ME, but it is most important to stress the fact that cases of ME or mild or even moderate severity may have normal muscle power in a remission. In such cases, tests for muscle power should be repeated after exercise.”

All patients learn this the hard way – if they do too much, they will suffer payback. What constitutes too much varies from person to person and day to day, but can only be determined by the patient themselves, and not by anyone who lives outside of the patient's body. For our members it can be brushing their teeth, eating a meal, sitting up in bed for a few minutes, or having another person in the room. In other words, activities which are essential for life.

Until this mechanism is understood and researched, it is of paramount importance that patients are not forced to do too much, nor encouraged to do too much or have it suggested to them that they will recover if they push through the symptoms. There may be a subset of mildly affected people for whom this is the case, but we feel that they would mostly discover this for themselves (or with suggestions from loved ones). Most people with ME naturally do as much as they can within the confines of their illness and actually need reminders to NOT push themselves so hard.

Many of our members have been less severely affected; a sizeable number of these, perhaps the majority, became severely affected because of GET, CBT or an approach based on these concepts. Stories such as individuals who walked into hospital and as a result of their treatment there could not walk out again – should be unusual and a warning to those using these therapies - but instead are commonplace in our community.

There have been many patient surveys, carried out by different organisations, which repeatedly show that respondents have suffered harm because of GET and, to a lesser extent, CBT. This resume from 2011 gives results from 9 surveys.

Table 2. Pooled Data of Harms from GET, CBT and Pacing reported in Surveys

Therapy	Sample Size	Harms ^a (N)	Mean rate of harms (%)	Range
Graded Exercise Therapy (GET) (or similar terms) ^b	4338	2223	51.24%	28.1 - 82%
Cognitive Behavioural Therapy (CBT) ^c	1808	360	19.91%	7.1 - 38%
Pacing (or similar terms) ^d	5894	152	2.58%	0.2 - 9.3%

^aThis includes any degree of harm e.g. both "somewhat worse" and "a lot worse" from the ME Association survey [85].

^bTaken from [75,78-80,82-85]; ^cTaken from [80,81,83-85]; ^dTaken from [79,80,83-85]

<https://iacfsme.org/PDFS/Reporting-of-Harms-Associated-with-GET-and-CBT-in.aspx>

Results of the 25% ME Group Follow-up Survey were made available to Key Group members of the CMO's Working Group on CFS/ME in April 2001. We informed the government that our members said that Graded Exercise and CBT were the most unhelpful strategies for their illness; we feel that policy on treatments has not moved forward in the past 18 years.

We also produced a report in 2004 which showed of our members who had used GET and CBT, 95% had been made worse with GET and 93% with CBT.

If GET was a pharmaceutical drug, its use would not be countenanced. The cost to the individual and to society of people becoming as ill as many of our members are should be an outrage to the medical community. We do not understand why the lessons of our members are not taken on board, why these surveys were completely ignored in the design and publication of the PACE trial, and why NICE are even considering keeping these bogus 'therapies' in their guidelines for ME/CFS.

It goes without saying that our members are suffering a number of serious symptoms which affects their quality of life enormously. It is unconscionable that doctors are prescribing therapies which make it more likely that further numbers of patients will also become severely affected – and that NICE is actively contributing to this number by recommending GET and CBT despite our pleas over many years. The enormous sadness for us is that we shouldn't have had to become this ill – and that society and NICE did not care enough to listen to us. There is a chance for this committee to STOP the abuse now, at this moment in time, by removing these therapies from the guidelines with immediate effect.

Yours sincerely,
25% ME Group

May we refer you to resources on our website:

<https://25megroup.org/factsheets-and-leaflets>

REF:

[March-2004-Severe-ME-Analysis-Report.pdf](#)

[Severely-Affected-and-Graded-Exercise.pdf](#)

[Follow-Up-Survey-on-People-with-Me.pdf](#)