Invest in ME Research

Press Release November 2020

NICE Draft Updated Guideline on the Diagnosis and Management of Myalgic Encephalomyelitis (ME or ME/CFS)

For Immediate Release 10th November 2020

Today the National Institute for Health and Care Excellence (NICE) issued a press release regarding myalgic encephalomyelitis (ME) [1].

Invest in ME Research is a stakeholder in the NICE guidelines for ME and has commented frequently on the NICE response to ME over the years [2].

Until the charity is able to examine the full draft guidelines document then our comments relate only to this NICE press release.

From the NICE press release it appears that GET is to be removed as a recommendation from the new NICE guidelines and the recommendation of prescriptive CBT that was manufactured for ME is to be replaced by an offer of supportive CBT as proposed for use in other chronic illnesses.

This was predictable and predicted – creating a balance of action and inaction, satisfying some of the demands from patients and retaining some of the status quo that merely props up previous flawed research.

Invest in ME Research commented on the previous guidelines back in 2006/2007 [3].

In January 2018 the charity had lengthy correspondence with NICE Guidelines director Professor Mark Baker [4] and requested that NICE remove immediately the recommendations for the deleterious therapies (CBT and GET) from the existing guidelines while the new guidelines were being drafted -

> *CBT in the existing NICE guidelines is tightly connected to GET as it asserts that fear of exercise and false illness beliefs perpetuate the condition.*
>
> *CBT and GET are the two major components causing the damage being done to people with ME. Their continued use affects everything. We do not accept that "in particular" GET is not acceptable.*

CBT must be removed also in parallel with GET.

By leaving CBT as a recommendation, you will leave the door open for continued funding of the same bogus research that has monopolised and compromised the lives of people with ME and their families for so long.

It is unacceptable.

We are telling you directly that leaving both CBT and GET as recommendations in existing (or future) guidelines will damage the health of people with ME.

If the treatments mentioned (CBT and GET) are already accepted to be "inappropriate", "unacceptable" or "unsuitable" as recommended by the existing guidelines then your (and NICE's) duty and obligation to sick and vulnerable patients is to remove them immediately.

There is no other logical course to take. [4]

Professor Baker and NICE declined this request.

When the new NICE guidelines are finally published in 2021 it will be three years since we wrote to Professor Baker. We wonder how many more ME patients' lives will have suffered over those three years by being prescribed, or coerced into trying, these harmful therapies based on the still existing NICE guidelines.
This could have been avoided if NICE had agreed to Invest in ME Research's request in 2018 to remove CBT and GET from the existing guidelines – or on the many occasions before that.

The NICE press release states that the draft guidelines

> "..***stresses the need for a tailored, individualised approach to care based on establishing a partnership between the person with ME/CFS and those providing their care that allows joint decision making and informed choice***."

It is an interesting statement as even fairly recently we have a story of a civil servant, an ME patient, being coerced into taking CBT and GET by an insurance company due to the existing NICE guidelines recommendations - and where the patient has stated that they would be made worse [5].

The NICE press release states

> "***The draft guideline also highlights the importance of ensuring that people remain in their 'energy envelope' when undertaking activity of any kind. It recommends that a physical activity programme, in particular, should only be considered for people with ME/CFS in specific circumstances.***"

We hope that this message is conveyed to the DWP and that benefits assessors will be so forewarned and not coerce vulnerable patients to accept any work under threat of cancellation of their benefits.

The NICE press release also states that any physical activity programme should begin by establishing the person's physical activity capability at a level that does not worsen their symptoms. It also says that a physical activity programme should only be offered on the basis that it is delivered or overseen by a physiotherapist or occupational therapist with training and expertise in ME and is regularly reviewed.
We assume that properly trained professionals who are capable of administering this oversight and have the requisite expertise would be available for patients, if desired by the patient.
Will all the physiotherapists and occupational therapists currently involved in ME get retrained as the past 13 years of CBT and GET advice has been based on a false illness belief model of ME?

IiMER hope that these changes to previous recommendations will filter through to insurance companies as soon as possible. Too many patients have lost their livelihoods and health on claims that CBT and GET are curative and necessary to go through before any claims could be made. NICE should be accountable for this damage.

Early diagnosis of ME is to be welcomed though there is still no specialisation in ME so how effective this will be in practice is determined by attitudes of clinicians and consultants.

We are happy to see a NICE Guidelines director acknowledge what Invest in ME Research has been stating for years, that everything has been

> "***.. compounded further by a lack of effective treatments, wide variation in access to services, and by controversy over the use of graded exercise therapy and CBT that has served only to alienate many people with ME/CFS..***"

something the charity pointed out when NICE formed their "balanced" working group in 2018 [6].

All of these changes could have been taken on board in 2007 when patients took NICE to judicial review [7]. Yet NICE are only now deciding to take steps to remove these flaws in their previous guidelines

NICE has been forced by some organisations such as Invest in ME Research (those who have steadfastly been on the side of the patient) to accept that the existing guidelines are and have been unfit.

And, tellingly, the NICE statement implicitly recognises the failure of national research councils to fund and initiate adequate research into ME by including this observation –

> ***"The committee wasn't able to make any recommendations for treatments because of a lack of evidence of effectiveness"***

The reason for a lack of evidence is a result of a lack of funding for fundamental biomedical research – a task that has been taken up instead by patients and carers [8].
Thanks to patients it has been realised how important it is that the biomedical research needs to be performed that allows accumulation of scientific data, collaboration with other institutes and possibility of a treatment for a subgroup of ME.

Whilst NICE might well expect to be congratulated for finally listening, in part, to the needs of people with ME, then it would be premature to think that all is now well.
Removing GET was always going to happen thanks to the age of social media where the paucity of any evidence base and the overwhelming rejection by patients meant that GET could never survive serious and constant scrutiny as a useful therapy for ME.

Invest in ME Research will examine the full draft document to determine whether the latest NICE guidelines do in fact provide much needed clarity, and whether it sets new standards for health professionals and ensures that people with ME have access to the right care and support.

However, the NICE press release shows how little has changed for people with ME in UK over thirteen years.

NICE entitled their press release ***"..the continuing debate about the best approach to the diagnosis and management of myalgic encephalomyelitis.."***

The fact that they still feel the need to refer to a "continuing debate" illustrates that NICE probably still has a lot to learn to get to where patients were some thirteen years ago – the lost years.

Invest in ME Research has long stated that the guidelines must surely be created to benefit patients and to assist clinicians (and researchers).

Yet the existing NICE guidelines have been allowed to remain for thirteen years with flawed recommendations.
How many lives have been harmed over these thirteen years since the previous guidelines were created – guidelines that were criticised by most charities at the time?

Just to put into context the failure of NICE and its supporting organisations –

- 13 years covers the teenage years and young adulthood of a child diagnosed at the age of 13;
- it covers the early adulthood of somebody diagnosed in their twenties;
- it covers the middle age years of those diagnosed in late adulthood;
- it covers the later years when diagnosed in their forties.

These years are forever blighted, these times are never recovered.
They are lost.

So no, no reason for congratulations.

NICE failed people with ME and their families for thirteen years despite having many chances to improve the situation. Yet NICE has never been made accountable.

We can only hope that there is enough change in the new guidelines to overcome the misinformation about ME that has been allowed to be built up over the years despite objections from the patients.

The charity's full analysis of the draft guidelines will be completed in due course.

References:

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1 NICE Press Release - NICE draft guidance addresses the continuing debate about the best approach to the diagnosis and management of myalgic encephalomyelitis (ME or ME/CFS) - https://tinyurl.com/yy42dgmu

2 NICE commentary - https://tinyurl.com/y4vxfmzu

3 Response to NICE Guidelines 2006/7 https://tinyurl.com/y3odlbc4

4 Letters to NICE Director Professor Mark Baker https://tinyurl.com/yyhl6e2r

5 Letters to NICE Director Professor Mark Baker Summary https://tinyurl.com/y4h7uc4e

6 NICE Guidelines Development - Turning a farce into a shambles https://tinyurl.com/yyycg93e

7 NICE Guidelines – What's Next? https://tinyurl.com/y5moj4ht

8 UK Charity Agrees Major Funding Award https://tinyurl.com/y4ln78st

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Notes for editors

About Invest in ME Research
Invest in ME Research (charity nr 1153730) is an independent UK charity finding, funding and facilitating biomedical research into ME.
Invest in ME Research is run by volunteers - patients or parents of children with ME - with no paid staff. Overheads are kept to a minimum to enable all funds raised to go to promoting education about ME and facilitating and funding biomedical research into ME. The charity organises an annual International ME Conference Week in London that includes a two-day research Colloquium, a Young/Early Career Researcher conference, a Clinicians Workshop and a public International conference that regularly has delegates from twenty countries attending.
The charity's efforts are on developing the Centre of Excellence for ME to maintain a strategy of high-quality biomedical research into the disease and encouraging European collaboration in research and development of clinical expertise.
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