

Submitted on behalf Suffolk Youth & Parent Support Group¹: Norfolk & Suffolk Service Design and Service Implementation Group² and Colchester MESH Essex

RE: NICE guideline on CG53 Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (or encephalopathy) ³: diagnosis and management: Surveillance consultation

I received the following notice last week via the NICE stakeholder, ME Association, "**Bad news to the MEA from NICE: no review considered necessary.**"⁴

The bulletin related to the following;

NICE - National Institute for Health and Care Excellence communication;
Level 1A, City Tower
Piccadilly Plaza
Manchester
M1 4BT

Tel: 0300 323 0140
Fax: 0845 003 7784

www.nice.org.uk

Dear Colleague

RE: NICE guideline on CG53 Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management

I am writing to let you know that, **after considering the evidence and consulting with experts,** we have provisionally decided not to update this guideline. We would like to hear your views on the proposal.

To comment, please see the consultation page on our website.

The consultation will close at 5pm Friday, 21 July 2017.* We regret that we will not be able to consider any comments after this date.

We would like to thank you for your continued support and your interest in NICE guidelines.

If you have any queries please do not hesitate to contact me at surveillance@nice.org.uk

Kind regard

Surveillance Team
NICE Centre for Guidelines
National Institute for Health and Care Excellence
Level 1A | City Tower | Piccadilly Plaza | Manchester M1 4BT | United Kingdom
www.nice.org.uk

*** The Consultation breach has been resolved; NICE Enquiry (our ref EH82669) 11/07/17**

¹ <http://suffolkmeandyou.blogspot.co.uk/2016/05/>

² <http://nandsme.blogspot.co.uk/>

³ Myalgic encephalopathy is not a recognised and validated condition and this name should be removed. Capitals should be used to identify ME and **CFS**. :**Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**

⁴ <http://forums.phoenixrising.me/index.php?threads/bad-news-to-the-mea-from-nice-no-review-considered-necessary.52648/>

1. Do you agree with the proposal not to update the guideline? No.

To Surveillance Team; you state;

“The clinical guideline for CG53 Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management has been checked by NICE for the need for update. **Registered stakeholders for the guideline are invited to comment on the provisional decision** via this website. Organisations not registered as stakeholders are not able to comment, we recommend that you register as a stakeholder or you contact the [registered stakeholder organisation](#) that most closely represents your interests and pass your comments to them. Note that the [provisional review decision](#) presented here does not constitute NICE's formal decision on this guideline. The decision is provisional and may change after consultation.”

Consultation dates: **10 July 2017** (9am) to **24 July 2017** (9am)

I have had to challenge the NICE Consultation period 10th-21st July and secure an extension; and have issued an FOI-to secure material information to inform my response (but which will not be made available within the necessary timeframe).

The provisional decision issued and now under consideration by NICE: may endanger compliance with the following NICE Terms of Reference⁵ in the footnote below.

Having looked at the NICE website, I can see no evidence that the NICE process of review is in the public interest and complies with the transparency and openness required by the public who have a right to interrogate the NICE decision making and question any NICE guidance fitness for purpose.

2. Do you agree with the proposal to remove the guideline from the static list? Yes.

A review of CG53 needs to be done, to achieve compliance with and to meet the requirements of the 2012 Health and Social Care Act & the 2003 Standards for Better Health - which in turn inform the Care Quality Commission Core Requirements, of which 3 of the 5 core requirements used in inspections are relevant.

The NICE pathway process on the NICE website for CFS and ME Guidance which is under review, appears to be incomplete, limited and inadequate (see my annotations of your “patient experience flowchart “on pages 8 and 11 (of my response).

Most importantly, the decision not to review may lead to noncompliant with the current legislative approach and relevant Standards for Health which govern service provision.

⁵ <https://www.nice.org.uk/Media/Default/About/Who-we-are/20140910-smt-tors-final.pdf>

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Senior Management Team

Standing Orders and Terms of Reference

Terms of Reference

Overview

1. constructing effective relationships with partner organisations and maintaining good communications with the public, the NHS, social care and local government and with the life sciences industries

identifying and mitigating the risks faced by the Institute.

The 2007 NICE guidance and review process appears inconsistent with the requirements currently placed on health care providers (many of whom follow the 2007 NICE Guidance, in principle, to determine provision).

We suggest that the 2007 guidance is now inconsistent with and potentially at odds with the requirements and aims of the Health & Social Care Act 2012 and Care Act 2014.

It is non compliant with the 2003 “Standards for Better Health” - Aims and specific Standards.

3. Do you have any comments on areas excluded from the scope of the guideline?

Yes.

The surveillance report considers and says it resolves the question of whether the guideline should be changed to align with new conclusions in the US about the diagnosis and the management of ME/CFS.

ME and CFS is an International problem and needs dealing with as such. There is a growing international consensus supported by patients, carers, clinicians, medical researchers and some NHS commissioning teams with which NICE should align its guidance.

Furthermore, recent case law⁶ will require that NICE show due diligence to assess the need to review their decision making against any new legal benchmarking.

We request that either the guideline be revised to include the vital information now excluded, or that NICE develops a new surveillance report that directly addresses these ethical considerations in a way that reflects the organisation’s commitments to the ethical practices described in the NICE Social Value Judgments document.

We draw your attention to the;

APPRAISAL OF GUIDELINES FOR RESEARCH & EVALUATION INSTRUMENT : The AGREE Collaboration September 2001. Agree.org - An international tool for the assessment of practice guidelines. It has recently been updated.

I am aware to date of the following;

Professor Mark Baker, NICE⁷

“2.1 The Chairman introduced Prof Baker who explained he had been in post for about two years. The Professor said he would start with an explanation of the process by which subjects come before NICE. Originally they had just responded to whoever wanted guidance. Then around 2005-6 a formal process of topic selection, with specialist panels, was set up. That process was changed around the end of 2010 when the main political parties preferred “standards” to guidelines in the NHS. In March 2012 a Library of Quality Standards Topics was established; it included a number of NICE guidelines but ME/CFS was not among them and he did not know why. It was not feasible to

⁶ The Montgomery case has changed the way in which guidance now needs to be given. NICE can no longer rely on only the best available evidence in their opinion, they have a duty to identify all risks and benefits.
https://www.supremecourt.uk/decided-cases/docs/UKSC_2013_0136_Judgment.pdf
<https://mdujournal.themdu.com/issue-archive/issue-4/informed-consent-a-year-on-from-montgomery>

⁷ <http://www.meassociation.org.uk/2014/07/forward-me-group-minutes-of-meeting-at-house-of-lords-25-june-2014/>

update or change guidelines not in the Library until at least 2017. The Library was now the responsibility of NHS England, not of the Department of Health.”

The Groups observations

1. That recommendations are made apparently by “**topic experts**”⁸ who are unknown to the public or anyone outside of NICE including interested politicians.
2. That the “**research**” done and **evidence base** for these recommendations are unknown to the public or anyone outside of NICE, including interested politicians.
3. That likewise, the “**Surveillance Team**” at NICE are unknown to the public or anyone outside of NICE including interested politicians; so their competency and possible **conflicts of interests and declaration** currently have not been released to public scrutiny.
4. That this is a selective and discriminatory and inconsistent approach by NICE who have released the footnoted information for other NICE consultations which, Norfolk and Suffolk Groups, have contributed to recently as partner stakeholders together with other registered stakeholders.⁹
5. The NICE Equality Impact Statement for CG53 should be available for public scrutiny.
6. UNCRPD¹⁰ compliance is required as well. The current guidance process is incompatible with the UK Conventions on Children, the disabled and women.

I would like to ask the following question of the Surveillance Team (in addition to my EH82739 Freedom of Information request- **as I have received a notice that NICE seem to be too busy to oblige me with information: it is unfortunate that response to the FOI will not be available - during the consultation period;**

- 1) **The 2007 NICE Guidance and review process does not appear to have been assessed against the new legislative requirements enacted over the last 10 years.** How can “*no review needed*” therefore be a recommendation?
- 2) Where is the evidence for the “*no review needed*”?
- 3) Who are the individuals within NICE who suggested this decision?
- 4) What factual data and evidence was used to arrive as this recommendation?

⁸ Source: UK House of Lords Date: July 19, 2017

URL: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2017-07-10/HL637/>

Ref: <http://www.me-net.combidom.com/meweb/web1.4.htm#westminster>

⁹ NIHCE draft guideline 'Intermediate care (including reablement)' <https://www.nice.org.uk/guidance/GID-SCWAVE0709/documents/draft-guideline>

Question made during correspondence with NICE Team- “The Institute responded to my comments on behalf of *** Group at guideline **scope stage ;Regaining Independence Guideline Scope Consultation**. Scoping exercise with response from **developers's**

<https://www.nice.org.uk/guidance/gid-scwave0709/documents/intermediate-care-including-reablement-scope-consultation-comments-table2>

“I anticipate that this will be an important issue for the **Guideline Committee** to consider’. *Can you direct me to any point in the draft that is indicative of the **Guideline Committee** having considered this ‘important issue?’* “
Contacts- Danielle Conroy Guideline co- ord 0160 41604008 Nick Staples, the project manager was out of his office 020 7045 2076

¹⁰ The presently pervasive ambit of the guideline carries freight in the shape of distortion of the concept of patient choice and “no decision about me without me”- the UN Convention on the Rights of People with Disabilities [UNCRPD].

Article 19 of the UNCRPD makes clear that Independent Living is not necessarily about disabled people doing things for themselves but rather about having choice and control over the support they need to achieve their goals. “The focus for all to benefit from a particular approach, CBT and GET in the draft Guideline is both unrealistic and in our view indicative of a highly restrictive understanding people with ME’s needs and safety. This can be addressed by dealing with the need to clearly delineate and circumscribe the relevance of the guideline. In doing so the guideline committee and development group may wish to bear in mind that ‘autonomy’ I the core principle for personal choice.”

- 5) NICE Guidance **CG53** was controversial in 2007:10 years on, it is none the less so.
- 6) Professor Mark Baker from the National Institute for Health and Clinical Excellence (NICE) *“As can be seen from the Minutes, Professor Baker accepts that the NICE guideline on ME/CFS is no longer meeting the needs of people with ME/CFS and it fails to take proper account of the wide variety of clinical presentations and disease pathways that come under the ME/CFS umbrella.”*¹¹ Surely therefore, it beggars belief that this provisional review decisions has been announced?
- 7) Do the topic experts and the Surveillance Team not agree, that the suggestion of recommending “no review”, (this is added to the potential breach of Government protocol and guidance on public involvement and consultation I identified¹²) once again could trigger and lead to a judicial review challenge by those aggrieved and harmed by the current guidance?
- 8) The review exercise to date does not appear to be underpinned by a fair, sensible or robust process. Surely-NICE-have a duty to engender public support or confidence in the guidance?

4. Do you have any comments on equalities issues? Yes.

This review appears inconsistent with other NICE consultations I have recently contributed to¹³ I wish to ask NICE to confirm whether it's approach is equitable with other NICE reviews and processes?

To summarise

A review of CG53 needs to be done, to achieve compliance with, and be reflective of the following; the 2012 Health & Social Care Act, Care Act 2014, the 2003 Standards for Better Health (which underpins the working practices of the CQC and their core requirements).

NICE Guidance currently fails to separate the “sheep from the goats”; i.e.the true presentations of ME and CFS as opposed to patients with vague non specific fatigue. This is it's greatest failing.

Because the current guideline and emphasis directs patient care down a vague fatigue and mental health approach, the result is that it effectively obstructs patients' access to appropriate biological testing, treatment and support. Misdiagnosis is rife with peer reviewed research indicating it running at some 40% misdiagnosis.¹⁴ This results in patient harm, death and NHS “NEVER” events reported to Healthwatch locally. To avoid this ethical violation, we request that the guideline be revised to present a truthful, helpful guidance reflective of the current debate, emerging exciting

¹¹ <http://www.meassociation.org.uk/2014/07/forward-me-meeting-and-the-nice-guideline-on-mecfs-statement-by-the-me-association-10-july-2014/> <http://www.mereseach.org.uk/information/publications/misdiagnosis-on-a-grand-scale/>

¹² NICE Enquiry (our ref EH82669) 11/07/17

¹³ [Intermediate care including reablement](#)

¹⁴ “The presently pervasive ambit of the guideline carries freight in the shape of distortion of the concept of patient choice and “no decision about me without me”- the UN Convention on the Rights of People with Disabilities [UNCPRD].

Article 19 of the UNCPRD makes clear that Independent Living is not necessarily about disabled people doing things for themselves but rather about having choice and control over the support they need to achieve their goals.

The focus for all to benefit from a particular approach, CBT and GET in the draft Guideline is both unrealistic and in our view indicative of a highly restrictive understanding people with ME's needs and safety. This can be addressed by dealing with the need to clearly delineate and circumscribe the relevance of the guideline. In doing so the guideline committee and development group may wish to bear in mind that ‘autonomy’ is the core principle for personal choice.”

new international research findings, and state of play about the nature and optimal management of ME/CFS.

A reminder as Sir Mark suggests you use “Standards:

The Nice review needs to reflect services capacity to deliver the following;

STANDARDS FOR BETTER HEALTH

Aims (my emphasis)

*7. The final but key aim of these standards is to underpin the delivery of high quality services which are fair, personal and responsive to patients’ needs and wishes, which are provided equitably and which deliver improvements in the health and well-being of the population. This aim can only be achieved if these benefits are delivered to **all** groups within our society. The standards must therefore be interpreted and implemented in ways which:*

- **Challenge discrimination**
- **Promote equality of access and quality of services**
- **Support the provision of services appropriate to individual needs, preferences and choices**
- **Respect and protect human rights**
- *Further the NHS’s reputation as a model employer*
- *Enable NHS organisations to contribute to economic success and community cohesion.*

This spells matters out clearly;

STANDARDS FOR BETTER HEALTH require following;

How the standards framework is structured

16. The standards set out in this document are organised within seven “domains”, which are designed to cover the full spectrum of health care as defined in the Health and Social Care (Community Health and Standards) Act 2003. The domains encompass all facets of health care, including prevention, and are described in terms of outcomes. The seven domains are:

- *Safety*
- *Clinical and Cost Effectiveness*
- *Governance*
- *Patient Focus*
- *Accessible and Responsive Care • Care Environment and Amenities • Public Health*

Previous correspondence with NICE

Dear Ms Robinson

Thank you for contacting the National Institute for Health and Care Excellence (NICE) with regards to our guideline on chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management (CG53).

I have highlighted your feedback regarding the length of the consultation period to the guidelines team, for their consideration.

I can confirm that the closing date for the consultation has been amended, and it will now close at 9am Monday 24 July 2017.

As you know, our website originally said the closing date was 21 July, but this has now been changed for consistency with our standard, published processes (as per point 14.1.3 of the NICE guidelines manual).

Kind regards,

Natalie

Communications Executive
Corporate Communications

National Institute for Health and Care Excellence
Level 1A | City Tower | Piccadilly Plaza | Manchester M1 4BT | United Kingdom

Tel: 0300 323 0141 | Fax: 0300 323 0149

Web: <http://nice.org.uk>

The FOI issued by me to inform the process however, will unlikely be delivered within the consultation time frame.

Dear Mrs Robinson

Thank you for your follow-up questions.. Please see further information required (attached).

1. Contributors and declarations of interests- The Guideline Committee
2. Members of the Committee and other contributors to the guideline
3. declared any relevant interests

[Add guideline number to hyperlink] in line with the NICE conflicts of interest policy

As you have separately requested the same information under the Freedom of Information Act, your request will be considered under the Act. We will respond as soon as possible (and certainly within the statutory timescale of 20 working days, as defined by the Act).

Kind regards,

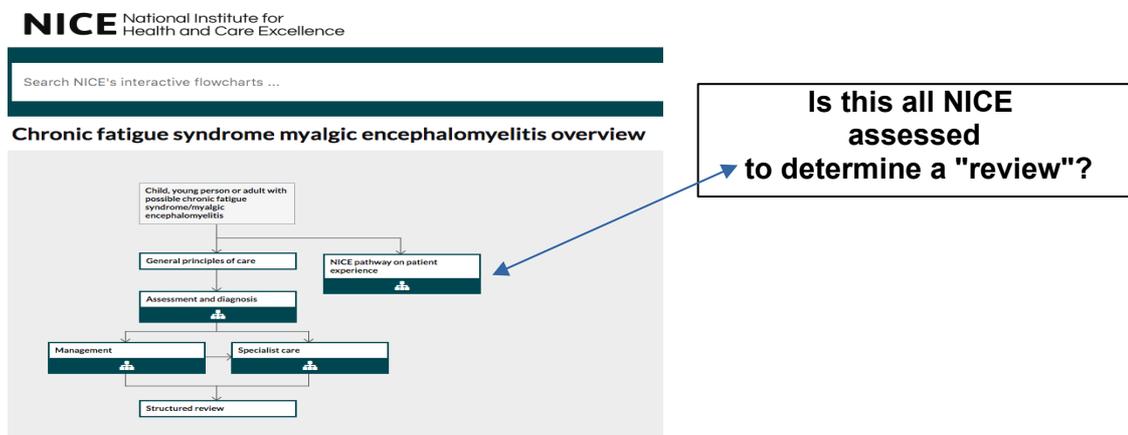
Natalie

I note that NICE only cite the "**Patient Experience** domain" from the legislation on their NICE Pathway for CG53.

<https://www.nice.org.uk/guidance/cg53>

Guidance

- [NICE interactive flowchart - Chronic fatigue syndrome myalgic encephalomyelitis](#)



“This guideline covers diagnosing and managing chronic fatigue syndrome (CFS) which is also known as myalgic encephalomyelitis (ME) (or encephalopathy). It aims to improve the quality of life for people with CFS/ME by setting out the care and treatment options that should be available for them.

Recommendations

This guideline includes recommendations on:

- [presentation](#)
- [diagnosis](#)
- [general management after diagnosis](#)
- [referral to specialist care](#)
- [managing setbacks/relapses](#)
- [review and ongoing management](#)
- [principles of care for people with severe CFS/ME](#)

Who is it for?

- Healthcare professionals
People with CFS/ME, their families and carers “

It is my understanding that the guidelines will be based on, and only on, the findings of RCT and studies that tick the boxes for what the Institute considers to be ‘evidence’, according to set parameters. Is the same true of the Guideline reviews?

When the ‘CFS/ME’ guideline was being developed (2007) those of us who are aware of the immense damage that exercise¹⁵ (GET) causes to PwME could cite real life examples, however,

¹⁵ <http://www.meassociation.org.uk/2015/05/23959/> Our CBT, GET and Pacing Report calls for major changes to therapies offered for ME/CFS | 29 May 2015

'NICE' were not interested in "informal" feedback from patients, support organisations and charities.

However, NHS STANDARDS FOR BETTER HEALTH require a new approach.

- Since the original CFS and ME Guideline was developed, the law regarding both Health & Social Care (2012) and government guidance on consultation, has radically changed.
- The climate has changed with Expert Patient initiatives and other requirements relating to patients which must be taken into account.
- The NICE guidance and Reviews therefore must be assessed against and compliant with new legislation; Health and Social Care Act 2012, and the 2003 Better Care Act important domains which are used by the Care Quality Commission in their assessment of services.
- Patient experiences can be found in NHS local services annual change audits and in local provider patient surveys. **Has NICE collated this publicly available information?**
- **There has been on going interest and a national survey of Patient experience**
<http://healthwatchtrafford.co.uk/wp-content/uploads/2015/03/Tired-of-explaining-ME-CFS-Summary-Report-by-Healthwatch-Trafford.pdf>
- Findings of CURRENT biomedical research studies which clearly contraindicate exercise (GET) must be evaluated.

Accountability

Care Quality Commission The Core Standards - these need to be re examined in relation to the current 2007 guidance.

What happens if it all goes wrong i.e. the guidance approach is suggested or proven to result in harm?- who, (if anyone) will be deemed at fault & accountable?

A service Provider will follow NICE or interpret the guidance. If that guidance is fundamentally flawed and not fit for purpose- harm can be done. Who is responsible? The provider or NICE?

There is ample evidence of the guidance being used and resulting in harm.

If NICE had collated patient experience feedback from Local Providers Annual Change Audits, which are a contractual Key Performance Indicators(KPIs) and Contractual obligations, they would have a clearer idea of where the NICE Guidelines are failing and would, via review, be able to start to put matters right.

Whilst this may not form part of the "formal" evidence base outlined in the parameter used by NICE, they are covered under the requirements of the 2012 Health & Social Care Act and the **STANDARDS FOR BETTER HEALTH identify the following- • Safety• Clinical and Cost Effectiveness • Governance • Patient Focus• Accessible and Responsive Care • Care Environment and Amenities • Public Health.** NICE cannot ignore these requirements nor sweep them under the carpet.

Comment from Dr Charles Shepherd, ME Association: Written question submitted to Professor Baker prior to the 2014 Forward ME¹⁶ meeting:

“Given the fact that ME/CFS covers a wide variety of clinical presentations and disease pathways, and that patient evidence consistently indicates that the majority of people find that CBT is ineffective; around 50% report that GET makes their condition worse; and over 90% find that pacing is the safest and most effective form of management, why does NICE continue to recommend the use of CBT and GET for everyone with mild to moderate ME/CFS?

“And why does the NICE guideline fail to provide any information or guidance on the management of a number of very disabling symptoms and problems associated with autonomic nervous system dysfunction – neurally mediated hypotension and POTS (postural orthostatic tachycardia syndrome) in particular?”

“This evidence, along with other evidence submitted during the recent consultation process on the proposal to place the NICE guideline on ME/CFS in the new static list, indicate that there is a need to review and revise a NICE guideline that was signed off nearly seven years ago.”

*Dr Charles Shepherd
Hon Medical Adviser, ME Association*

This was an extremely informative meeting with Professor Mark Baker from the National Institute for Health and Clinical Excellence (NICE) – he is their Director of the Centre for Clinical Practice.

As can be seen from the Minutes, Professor Baker accepts that the NICE guideline on ME/CFS is no longer meeting the needs of people with ME/CFS and it fails to take proper account of the wide variety of clinical presentations and disease pathways that come under the ME/CFS umbrella.

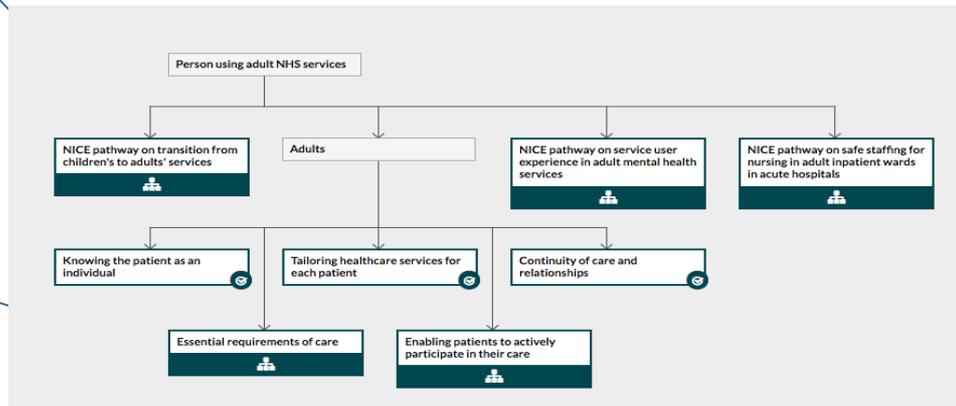
Professor Mark Baker, NICE¹⁷

2.1 The Chairman introduced Prof Baker who explained he had been in post for about two years. The Professor said he would start with an explanation of the process by which subjects come before NICE. Originally they had just responded to whoever wanted guidance. Then around 2005-6 a formal process of topic selection, with specialist panels, was set up. That process was changed around the end of 2010 when the main political parties preferred “standards” to guidelines in the NHS. In March 2012 a Library of Quality Standards Topics was established; it included a number of NICE guidelines but ME/CFS was not among them and he did not know why. It was not feasible to update or change guidelines not in the Library until at least 2017. The Library was now the responsibility of NHS England, not of the Department of Health.

¹⁶ <http://www.meassociation.org.uk/2014/07/forward-me-group-minutes-of-meeting-at-house-of-lords-25-june-2014/>

¹⁷ <http://www.meassociation.org.uk/2014/07/forward-me-group-minutes-of-meeting-at-house-of-lords-25-june-2014/>

Patient experience in adult NHS services overview



Woefully inadequate and sometimes a travesty of Justice- FII cases locally.

30% of patients are regarded as Severely Affected and effectively have no care being lost to the system

Unfortunately, as was stated above, NICE no longer decides which guidelines they are going to tackle afresh. This decision is now made by NHS England.

Questions I ask of the NICE Surveillance Team.

1. Who do I need to copy this into at NHS England?
2. Will the urgent need for a review of this outdated clinical guideline be raised once again with NHS England?
3. What was the response to the following letter -**Communication with NICE about the revision of the Clinical Guideline 53 Margaret Williams 12th March 2017** to Sir Mark Baker? <http://www.margaretwilliams.me/2017/open-memo-to-nice.pdf>
4. Please note, as a point of information, NHS Suffolk Commissioning, with whom Suffolk and Norfolk patients have been working alongside for 10 years, must be commended for their robust adherence to the NHS standards of;
 - **Promoting attempts to provide equality of access and quality of services**
 - **Supporting the provision of services appropriate to individual needs, preferences and choices**
 - **Respecting and protect human rights of their ME and CFS patients.**
 - Most of all they must be commended for having regard to NICE Guidance but rejecting aspects of it in favour of the International Consensus Criterial for ME and CFS. This has led to a new service specification and service development which is supported by patients and may better meet their specific needs in the future.

Barbara Robinson 03/08/17

I have incorporated the following;

Mr Crowhurst is one of our local coalition in East Anglian and formally was chair of the East Anglian ME group of which previously I was co chair.

Our group working with NHS Commissioning was overseen by LINK and now by Healthwatch, Suffolk and Norfolk.

We contributed to the National Healthwatch Survey on ME.

<http://healthwatchtrafford.co.uk/wp-content/uploads/2015/03/Tired-of-explaining-ME-CFS-Summary-Report-by-Healthwatch-Trafford.pdf>

A letter to Sir Andrew Dillon , Chief Executive, NICE

July 27, 2017

_Stonebird

27th July 2017

Sir Andrew Dillon,
Chief Executive,
NICE

Dear Andrew Dillon,

Re : Myalgic Encephalomyelitis

I have cared full time, for 25 years, for my wife who has a diagnosis of Very Severe ME, my Nursing Standard article "*Supporting people with severe myalgic encephalomyelitis*" is referenced by NICE in the original 2007 guidelines. In 2015 I was third place finalist, BJN, Nurse of the Year, for which I received an award specifically for my work in raising awareness of and advocating for people with Severe ME. I was Secretary of the 25% Severe ME Group charity for many years and represented the Group at the Gibson Parliamentary Inquiry.

In February the Joint Commissioning Panel for Mental Health document published **Guidance for Commissioners of services for people with medically unexplained symptoms – practical mental health commissioning**, which misinformed Commissioners that Myalgic Encephalomyelitis is a Somatoform, mental health disorder.

The response, in a letter to me, dated March 2nd, from the Co-Chairs of the Expert Reference Group for JCPMH Guide on Commissioning for MUS and the Co-Chairs of the JCPMH claimed that the: "*The content of the MUS guide is fully in line with NICE guidelines and with current*

practice. Should the relevant NICE guidelines alter, or the evidence in this area change, then we will revise the guide accordingly."

On March 15, NICE assured me that CG53 does not list ME as a somatoform disorder. Therefore the MUS guidelines cannot be correct.

I raised the misinformation in the JCPMH Report with the Department of Health, who confirmed that the Government recognises the WHO classification of ME as a neurological disease. They advised me to take the issue up personally with you.

I am interested to know what you can do to correct the misinformation that the JCPMH has given to Commissioners, especially given the serious potential implication in regard to the current consultation on CG53?

I also have the following questions, given that NICE has confirmed that it does not consider ME to be a Somatoform Disorder:

1. Can you tell me why NICE itself lists ME under "*Depression and anxiety disorders*" on the IAPT webpage and can you reassure me that it will be removed? That surely is as great a misrepresentation of ME as the JCPMH document, especially given the recognition in CG53 that "*the physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus and congestive heart failure .*"

<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-advice/iapt>

2. Can you explain the nature of IAPT's involvement in ME, especially in light of the the CDC's recent decision not to recommend CBT and GET? <http://www.meassociation.org.uk/2017/07/cdc-removes-cbt-and-get-as-recommended-treatments-for-mecfs-11-july-2017/>

3 Can you tell me what role, if any, IAPT played in the drafting of the recent CG53 Surveillance Document, which has been heavily criticised by all major ME Charities and thousands of patients for:

- its adherence to the widely disputed CBT/GET paradigm, which has been shown to make patients, especially the most severely affected, much worse.
<http://stonebird.co.uk/psurvey.pdf>
- its many references to the universally discredited PACE Trial
- its reliance upon vague diagnostic criteria that do not clearly identify or separate ME from mental health Chronic Fatigue (WHO F48). A wide definition helps no one; surely it is time to acknowledge that ?
- its scant regard for biomedical evidence

- its extraordinary decision not to update the 10 year old guidance which not only was condemned as “unfit for purpose” at the time, but continue to deny patients, like my profoundly physically ill wife, equal access to health care
- its failure to accurately represent international clinical practice
- its failure to remove outdated treatment recommendations and its pronounced self-circular psychiatric bias.

4. I am very curious to know the composition of the Topic Experts and their knowledge base and impartiality. What biomedical representation, if any, did you have? What clinical input, outside of the biopsychosocial school, was involved for unbiased appraisal of the biopsychosocial content? Can you tell me who the Topic Experts were? Were any of the Royal College’s involved?

5 Can you tell me why NICE only gave stakeholders two weeks to respond to the 56 page Surveillance document, making it incredibly difficult for those people who have ME themselves or full time carers, to have enough time to contribute adequately or at all.

6 Can you explain why NICE has relied heavily on an unfounded psychiatric theory of ME that is nothing more than that, with no real evidence itself, while ignoring the more than 9000 published papers that have been published world wide, detailing the biomedical abnormalities in ME?

7 Can you explain, given the statement in 2014 by Professor Mark Baker, Director of the Centre for Clinical Practice, at a Forward- ME meeting, that the Guideline *failed to address the real issues in ME/CFS, does not promote innovation and has had a disappointing impact on specialist care and commissioning issues*, why NICE has continued to stick to its outmoded, inappropriate, dangerous guidance?

<http://www.meassociation.org.uk/2014/07/forward-me-meeting-and-the-nice-guideline-on-mecfs-statement-by-the-me-association-10-july-2014/>

The Surveillance document does nothing, in my opinion, to challenge the misperception that ME is a mental illness, in fact it's decision to come off the static list, not for medical reasons, but because of the FITNET CBT/GET Trial reinforces the apparent psychosocial bias of the whole document and attitude of NICE.

If CG53 continues to contribute to a situation where people with ME are:

- misinterpreted as having a mental health issue
- where biomarkers are not sought for and relevant tests are proscribed

- where health professionals of every level are misinformed and their awareness skewed wrongly towards a biopsychosocial interpretation of a serious physical disease with ignored multi-system dysfunction, endangering lives and leading to mistreatment, misinterpretation, neglect and harm
- where the guidance on Severe ME fails to recognise the terrible suffering and multiple physical symptoms patients experience, making it dangerously irresponsible.
<http://www.stonebird.co.uk/principles%20of%20care.pdf>
- where ME is still not separated from and confused with mental health Chronic Fatigue and other poorly diagnosed diseases
- where services are geared towards a psychiatric diagnosis of wrong illness thought and deconditioning
- where patients are offered treatments that are inhuman, cruel, inappropriate and dangerous, because they are in direct denial of their physical reality- the potential for harm is enormous and terrifying in ME

then surely that is in contravention of your obligations under the Human Rights Act and the Equality Act?

The ME Community has been insisting for years that CG53 is not and never has been appropriate for patients with Myalgic Encephalomyelitis; the way forward is for ME to have its own biomedical Guideline and pathway, categorically without psychiatric interpretation and involvement.

Sincerely,

Greg Crowhurst

<http://www.stonebird.co.uk/>