

Is NICE ME/CFS guidance implemented in Wales?

a report from WAMES

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Background to NICE guidance for ME/CFS

People with ME were looking forward to the publication of the revised [NICE guideline](#) on 18th August 2021, because the draft guideline sent out for consultation in September 2020 indicated there would be a change in recommendations. They would no longer be following the 2007 guideline in recommending the discredited therapies of [GET](#) and [CBT](#) as treatments for ME and would be recognising the research evidence and patient experience of [Post Exertional Malaise](#) (PEM) as an essential characteristic of the condition and not just an optional 'symptom'.

There was widespread dismay when NICE ['paused' the publication](#) of the guideline hours before it was due to be published, even though it professed to be confident it had 'used its usual rigorous methodology and process' in updating the guideline. The ME community looked on with disbelief as the Royal Colleges & clinicians currently offering GET and CBT services challenged the recommendations *after* the final guideline had been 'signed off' by the guideline committee. In the end, following a Roundtable discussion, where no additional evidence to support the claims that GET and CBT were safe treatments had been offered, the guideline was published with the key recommendations intact, though alterations were made to the language.

Since WAMES was launched in 2001 we have been contacted by hundreds of people who wondered if they had ME but were unable to find a GP knowledgeable enough or even interested enough to make the diagnosis. We have also been told that some GPs refused to consider ME as a valid diagnosis and sent patients away telling them nothing was wrong with them or referred them to psychological services. In two Health Boards fatigue & pain services accepted ME/CFS patients, leading to a stream of complaints to WAMES that they didn't understand ME, and that the exercise therapy they practised didn't acknowledge the exercise intolerance of Post Exertional Malaise, and was causing relapse and making people more ill.

The publication of the 2007 NICE guidance recommended GET and CBT as first line treatments for ME/CFS, which strengthened the therapists' case for developing the 3 existing pain & fatigue clinics. The [2007 guidance](#) did make it clear that CFS/ME was a 'relatively common', 'disabling illness' with a 'complex range of symptoms', that it is important to 'acknowledge the reality and impact of the condition and the symptoms' and 'identify and manage symptoms early'. Many patients however told us they continued to struggle to find a doctor willing to take the illness seriously, to give a timely diagnosis or offer help with developing a management plan.

Background to NICE guidance in general

The NICE guidelines are generally heralded as the Gold Standard for healthcare, and more recently also social care providers. However in 2018 a disturbing poll by the magazine for GPs, [Pulse Today](#), showed that 76% of 515 English and Welsh GPs, believed NICE guidelines were only 'somewhat relevant' to their practice. The same survey revealed that more than 70% of GPs in England and Wales were departing from NICE guidance at least once a month, with one in ten ignoring it daily.

NICE now makes it clear at the beginning of each guideline that adherence to the guideline is not mandatory but:

When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

The Welsh Government sponsors NICE so [requires the NHS to heed guidelines](#):

All NICE guidelines and quality standards apply to Wales and are subject to Welsh legislation.

Individual Health Boards in Wales have NICE guidance implementation policies which acknowledge the expectation that they will 'take full account' of the recommendations made by NICE when commissioning and delivering services to patients. In addition, professionals are generally considered to have a professional duty to be aware of and to take full account of all applicable NICE guidance and to be ready to have documented reasons for not doing so.

Was the 2007 CFS/ME NICE guideline used in Wales?

Hearing patient and carer concerns that the 2007 NICE guidance for ME/CFS had not been implemented WAMES renewed attempts to understand what happens in GP consultations. A survey was set up in July 2021 to specifically ask if GPs were demonstrating any knowledge of the 2007 NICE guideline. The response was disappointingly low but the answers were in keeping with what we had previously been told over the last 15 years about doctor/patient interactions.

Many people were unable to take part in the survey as their GP consultations took place before 2007 or they had stopped consulting their GP about ME long ago. We were also aware that the short time scale and limited formats for response made it more difficult for the severely affected to respond. We also encountered doubt that anybody would be interested in the results of such a survey as 'all the NHS is concerned about these days is COVID'.

The low response means we can't draw conclusions about the percentage of GPs in Wales who do or don't use NICE guidelines, or how many patients are in fact happy with the advice they have

been given, but we can give snapshots of what people with ME are experiencing in their GP consultations. We didn't ask about harm caused by treatments in rehabilitation services as we focussed on experiences with GPs, although we have received many complaints about treatments over the years.

Survey responses

Key points

- Although the survey response was low the experiences participants gave echoed experiences previously recorded.
- No GPs specifically mentioned the NICE guidance in early consultations though later on a small number indicated they knew of a 'guideline' or 'recommendations' or NICE.
- Not all patients were offered blood tests to rule out other causes for symptoms.
- Only 20% of participants thought their GP/s showed some knowledge of CFS/ME symptoms
- Over 60% of GPs gave no indication they knew CFS/ME could be diagnosed within 4 months for adults, or 3 for children
- Half the participants received a diagnosis from their GP, a third were referred.
- Half the participants reported not having been treated with 'respect, sensitivity and understanding'. Some were reduced to tears, made to feel guilty or just ignored.
- Carers were frequently not given the chance to be involved in adults' care.
- Cognitive difficulties were not acknowledged and a written summary of the GP consultation was never offered.
- 78% of participants received no information about the management options recommended at the time by NICE though 22% thought they were given information about some management options.
- Only 4 GPs (23%) sought specialist advice for their severely affected patients CFS/ME advice.
- Only 1 patient was helped to develop a care / management plan.
- Only 4 people (13.5%) were told about the possibility of relapses
- 12 patients were offered a referral to fatigue/pain clinics, but patients did not find they had specialist knowledge of ME, and were not available in all areas.
- Only 2 patients were (8.1%) offered planned, regular reviews of how the management of their condition is being managed'.

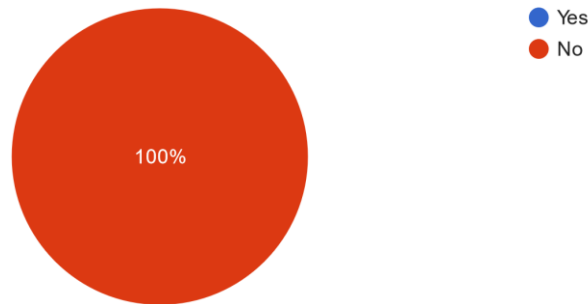
Survey results detail

There were 38 participants, and all except one was aged 35 or over. The 35 women and 3 men are spread out over 6 of the 7 local Health Board areas. The Health Board area that is not represented is Cwm Taf. The questions were designed to find out if GPs mentioned the NICE guidance during consultations or demonstrated any knowledge of the contents. We did not ask if the participants agreed with the content of the guideline, nor for a lot of detail, as this was not the purpose of the survey. Many patients volunteered the information that they had seen numerous GPs over the years in the attempt to find one who could help them, but we had not asked specifically how many each had consulted.

Q. Did your GP mention s/he knew about the 2007 NICE guidance?

No patient remembers their GP/s mentioning the guideline when they were seeking a diagnosis or early management advice, though one newly consulted GP mentioned them in July 2021. Occasionally GPs have gone online and not always extracted the most helpful information in the short time allotted to the consultation. [It is understood that the fact the guidelines weren't mentioned does not necessarily mean a GP didn't know there was a NICE guideline for CFS/ME.]

1. Did your present GP mention he/she knew about the 2007 NICE guidance? (If you did not consult this GP about a diagnosis please go to Q.7. If you... about the NICE guidance please continue with Q.2)
31 responses



"I spoke to him about latest research about a connection to autoimmune and he said we've done blood tests so you are fine. He said we use NICE and I need to refer you to the psychology team. He didn't offer any more help than that." (July 2021)

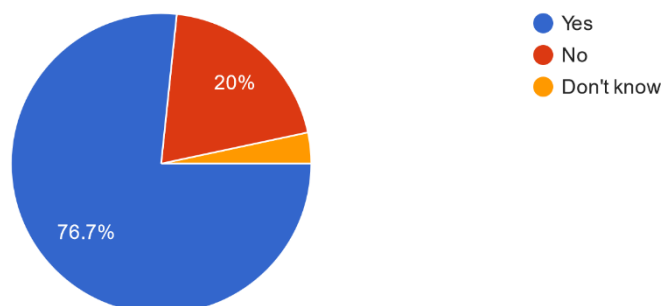
"Following routine bloods, I was called into surgery because of slight weight gain - new GP was confused about ME/CFS, used Internet to come up with GET, had no grasp of what that was, nor any understanding that the NICE Guidelines were under review. Whole thing was a tick box exercise, a wasted GP appointment and no help whatsoever to me."

"I have no recollection of the NICE recommendations being mentioned so my conclusion is the practice might not be aware of their existence"

Q. Did your GP do a series of blood tests to rule out other causes of your symptoms?

Most GPs did blood tests to rule out other causes of symptoms but of the 30 patients who were looking for a diagnosis during the relevant time frame, 6 remember being offered no blood tests, which raises the question of whether they had already decided that the symptoms were caused by a psychological condition, not a biomedical one.

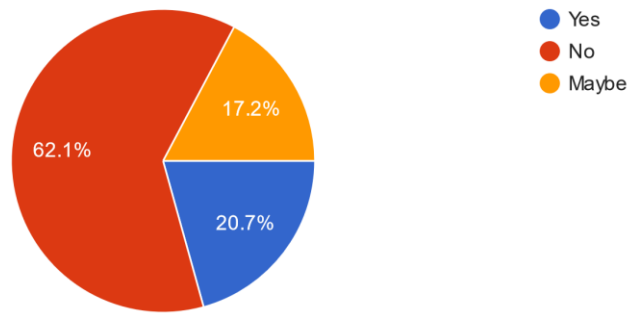
2. Did your GP do a series of blood tests to rule out other causes of your symptoms?
30 responses



Q. Did the GP show an understanding of CFS/ME symptoms listed in NICE guidance?

6 patients thought their GP showed knowledge of the symptoms mentioned in the 2007 guidance. 5 thought they might have known something. 17 GPs definitely didn't show any knowledge of the symptoms.

3. Did the GP show an understanding of CFS/ME symptoms listed in NICE guidance? [new disabling tiredness (fatigue) that means you can't do the th...ymptoms worsen after exercising or concentrating]
29 responses



Q. Did the GP show an understanding that a diagnosis in an adult should be made after 4 months of symptoms?

Of the 27 patients who were looking for a diagnosis during the relevant time frame only 5 GPs showed an understanding that a diagnosis could be made 4 months after symptoms began. A further 5 might have had some knowledge about that.

Many patients mentioned they had waited years for a diagnosis although we did not ask that question. They, like many others we have spoken to over the years, actively sought someone to confirm that their self-diagnosis was in fact correct.

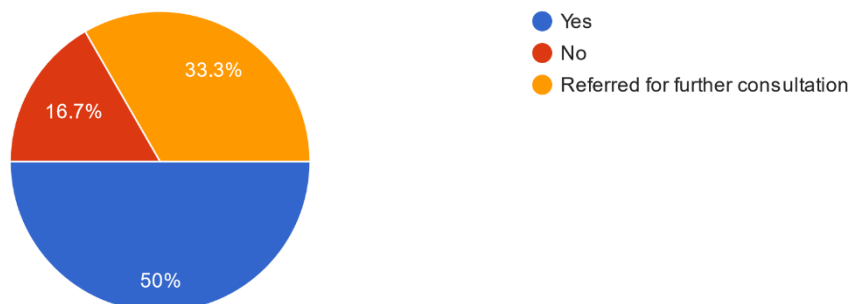
Q. Did the GP show an understanding that diagnosis in a child or young person should be made after 3 months, in consultation with a paediatrician?

Only 1 participant fell into this age range and did not believe their GP knew a diagnosis should be made within 3 months of experiencing symptoms.

Q. Assuming you met the criteria did you receive a diagnosis of CFS/ME?

14 patients received no diagnosis of CFS/ME with 9 of those being referred elsewhere. 15 did receive a diagnosis but it is unknown how long this took, which terminology some received, or if they were all accurate diagnoses.

6. Assuming you met the criteria, did you receive a diagnosis of CFS/ME?
30 responses



“I was diagnosed with ME about 14 or 15 years ago, having been referred through a previous GP... The diagnosis came through my referral to a team in Caernarfon...that was running a pilot rehabilitation course.”

“I was ill for over 4 years before being given a referral to an extremely part time chronic fatigue clinic for diagnosis. No follow up from clinic.”

“Referred to specialist at hospital for diagnosis. Specialist diagnosed then discharged me (and has since left and not been replaced).”

“The first doctor was convinced I was just depressed, however, the fatigue and exhaustion was causing the low mood. The doctor who diagnosed me was good and understanding, but she was 1 out of 4 I have seen.”

“GP insists that fibromyalgia and ME are more or less the same. Every time I ask for help he puts it all down to symptoms of these things.”

“GP refuses to have M.E. as a diagnosis - changed it from private consultant’s diagnosis of M.E. to CFS.”

“I was told my symptoms could be caused by 3 different reasons and they couldn't diagnosis which one it was because the symptoms I was experiencing were all the same, I was advised to research all 3 and keep a diary, also when I get a relapse there would be no need for me to contact the GP because there was no advice they could offer because there are no specialists in Wales.”

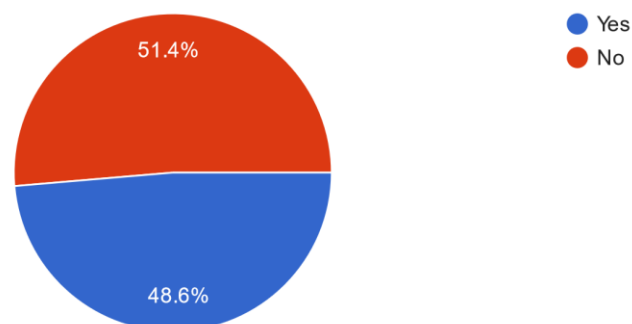
“The GP accepted I was unwell but really did not want to call my condition ME. I had previously been diagnosed by a paediatrician who held a clinic for adults. The GP wanted to name it PVFS. I was just grateful he treated me seriously as the previous GP told me that ME was just an excuse for shirking work”

Q. Were you treated with 'respect, sensitivity and understanding'?

Half of the participants were unhappy with the way they were treated, not having been treated with the 'respect, sensitivity and understanding' that all patients should experience. 18 were unhappy, but 17 were happy with the attitudes of their doctors.

7. Were you treated with 'respect, sensitivity and understanding'?

37 responses



“Where to start? The last GP I spoke to after a flare up was so rude I felt like reporting him.”

“My GP Practice certainly did not dismiss my ME/CFS and were more than happy to discuss the issue. They also made it clear that I could contact them at any point if my symptoms worsened.”

“It was as if I was an inconvenience.”

“The doctors... have poor understanding of the condition, especially the GPs, which of course then filters through to the rest of the practice. Not even a basic level of care, and crass remarks. I visit them as little as possible as it upsets me too much. This very much adds to a sense of isolation, hopelessness and being forgotten about.”

“I have left the surgery in tears on more than one occasion...the last time because I was told to 'bin' my watch I used to monitor steps and heart rate.”

“In my practice I asked my GP if she felt ME was a neurological or psychosomatic illness. She responded with ‘the jury is out regarding the diagnosis and I go by guidelines and what information is out there. As there is no clear diagnostic test, I find it hard to sit more one way than another’. I do appreciate her honesty and it’s made it easier for me to decide when I need to see her.”

“Even now 15 years on, I’m still being told that if, for example, I have HRT for the menopause, all my other symptoms would disappear. I am still not taken seriously. I’m told there is nothing for me.”

“I avoid going to my GP unless I absolutely have to. They treat the symptoms I present, but my illness is never mentioned even if I have made reference to it. It is usually completely ignored. I genuinely feel like they dislike or don’t believe patients with ME/CFS. e.g. I went to the doctors in desperation thinking maybe the neurologist who diagnosed me some years ago may be able to suggest something that could improve my life. The doctor said there was no point in referring me as the neurologist couldn’t help me. I suggested I paid to see the named consultant. She said she would refer me if I really wanted to be seen, as at least if I was paying I wouldn’t take up a place for someone else on the NHS. That day I rang the surgery back up and cancelled the referral I felt incredibly ashamed, and even more alone and depressed.”

Q. Did your family and carers have the chance to be involved in decisions about your condition/care?

Not all patients have family or carers involved in their care, but of those that did, the majority did not have the opportunity for them to be involved in consultations. Only 5 did, while 20 didn't.

Q. If you have severe CFS/ME were you offered a summary of all discussions?

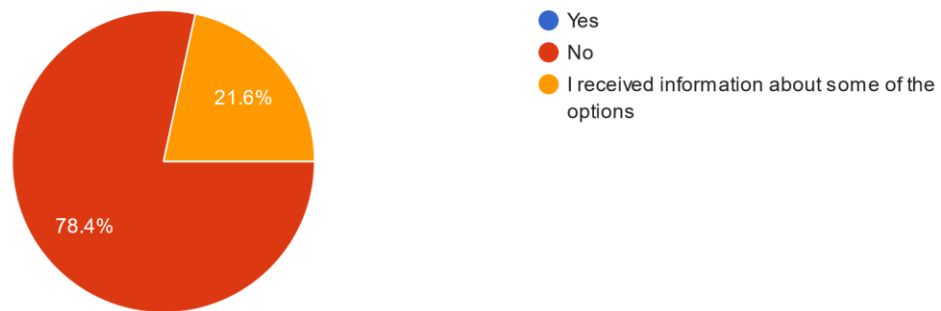
19 participants considered themselves to be severely affected at the time of consultation and none were offered a written or recorded summary of the discussions although cognitive problems are a major issue for many patients, not just those who are severely affected.

Q. Did your GP fully explain and discuss all the relevant options NICE recommends for managing your CFS/ME? (i.e. diet, sleep, rest, relaxation, equipment, adaptations, advice about work and education, reducing activity, pacing, complementary medicine.)

27 participants received no information about the management options recommended at the time by NICE, even though some options would have required no financial input from the practice or health board. 8 were given some information.

10. Did your GP fully explain and discuss all the relevant options NICE recommends for managing your CFS/ME? (i.e. diet, sleep, rest, relaxation, e...reducing activity, pacing, complementary medicine.)

37 responses



"I've never had a GP advise about pacing or offer a regular review. Exercise has been the only suggestion."

"The GPs at my local practice have turned down my appeals for help or support with my ME for years, despite the fact it has prevented me from being able to work even part-time."

"I get help for my severe ME from The ME Trust, via Zoom appointments with a specialist ME doctor. My GP practice are disbelieving of ME overall. They ignore my mention of ME in my appointments."

"No further help or review offered by GP. If I present at surgery for other issues and mention that I have ME they just ignore that."

"No help from GP who admitted she knows nothing about ME. I don't contact the GP about anything ME oriented, I get my support from online groups, ME Association etc."

"... I have however been fortunate in being allowed to self-inject Vit B12 although this was only after I presented the surgery with a file showing research in this area."

"No contact in between visits, or expected check-up. So can go years without a visit. Mainly self manage as GP has nothing to offer."

"No. My GP has insisted on Gardening Therapy, Exercise Therapy and Psychotherapy."

"My GP's answer to my ME was 'work, exercise, find hobbies that distract you. Look after your small children, they need you.'"

"My original GP (in the same practice) prescribed walking daily and pushing myself further each day, "as per recommendations", this led to the ME worsening and me ending up completely bedbound. He has now left the practice and my current GP tells me to keep doing what I'm doing because I'm not getting any worse. I've had no support from them at all. I've found my own way around ME via the online support and through ME associations."

Q. If you have severe CFS/ME did your GP get advice from a specialist?

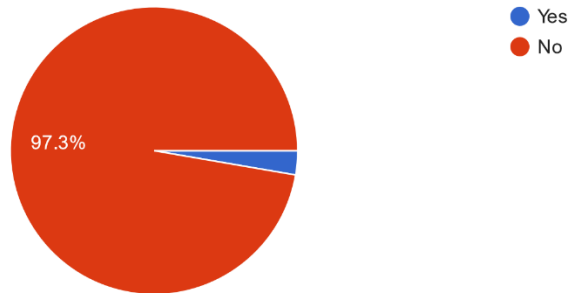
This was not relevant at the time for 17 patients, but GPs for 13 patients did not seek specialist advice for their severely affected patients. 4 GPs did seek advice (23.5%), though it is unknown who they approached.

Q. Did your GP work with you to develop a care plan (i.e. a health management plan) that suits you?

33 GP practices did not offer to help patients develop a management plan although NICE saw that as the GP's responsibility. Only 1 did.

12. Did your GP work with you to develop a care plan (i.e. a health management plan) that suits you?

37 responses



“I have received no after care or follow up support, which I am desperate for. There needs to be a long term plan rather than a diagnosis and send you on your way to cope alone.”

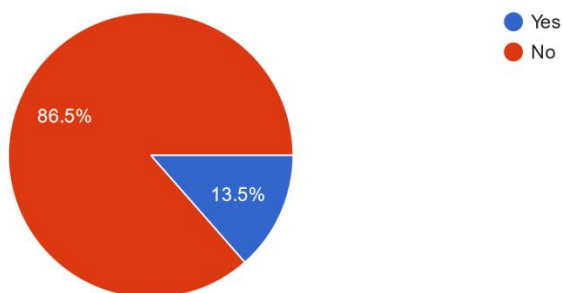
“Whilst my GP was friendly and understanding, I feel that I am just left to rot.”

Q. Were you told about the likelihood of relapses / setbacks?

Only 4 patients were told about the fluctuating nature of the condition with relapses being likely. This was not explained to the other 31. They were left to find out from their own experience and from other sources.

13. Were you told about the likelihood of relapses / setbacks?

37 responses



Q. Were you offered a referral to a specialist CFS/ME team?

12 patients were offered a referral to specialist fatigue/pain clinics, only one of which specialised in CFS/ME and all offered therapies based on GET and/or CBT, which was not found to be helpful. There were 2 clinics accepting ME patients in Betsi Cadwalladr Health Board and 8 patients received referrals to those. Powys also has a multidisciplinary clinic and 1 patient was referred there, though chose not to attend because what they had heard about it from others led them to believe the approach would not be helpful. 1 patient from the Swansea area also was given a

referral to their local pain and fatigue clinic. No referral was offered to the others and it is believed such services were not available in those Health Board areas.

“The newest GP has looked into referral on but found none could be made.”

“...a pilot rehabilitation course which I attended monthly over about 6 months. It was helpful in some ways but not others, such as graded exercise.”

“It took years to be referred to the ME clinic which is 50 miles away. Not a good service and not sure if it exists any longer.”

“I did attend an ME clinic... but I was just fed GET and pacing and virtually told to talk myself back to health.”

“I presented the varied symptoms of ME/CFS for nearly 6 years, while taking many weeks of work off while trying to recover from bouts, before I was given an appointment with the local CFS clinic.”

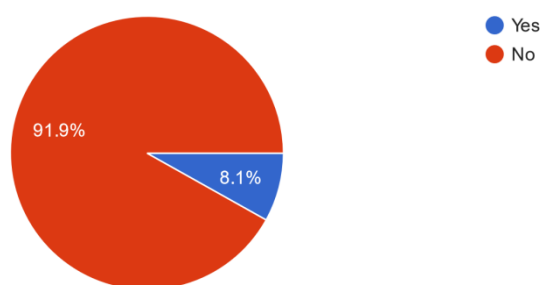
“There was no specialist service in the area. When I consulted a private doctor with a speciality in ME, the GP politely refused to read the report. He asked me to give him a verbal precis, which was difficult as I struggled to focus, concentrate & make sense of the medical language. He then told me he could not follow any of the treatment recommendations. The only thing he had to offer as an alternative was low dose antidepressants which I had previously found did not agree with me. He couldn't even refer me for standard CBT, as it wasn't available in the area. He was happy to prescribe standard treatments for individual symptoms or refer me for anything that could be unrelated to ME but appeared to have no knowledge or interest in ME itself.”

Q. Were you offered 'planned, regular reviews of how your condition is being managed'?

Only 2 of the participants were offered regular reviews of their management approach by their GPs.

15. Were you offered 'planned, regular reviews of how your condition is being managed'?

37 responses



“I have zero continuity of care. No one follows up on me. It seems no one cares.”

“I always felt I could bring new problems to my GP or discuss new treatments with him, as he was a caring person, but he wasn't interested in ME and could only comment based on his knowledge of other conditions. He would usually tell me that treatments that received promising results for ME in recent research weren't sanctioned for ME by the Health Board. Basically he had little to offer so a review was pointless.”

The future for ME/CFS and the NICE guideline in Wales

An estimated 13,000 people could be affected by ME/CFS in Wales, 250,000+ in the UK altogether. 25% of these are severely affected, being bed and/or house-bound. 10% are children under the age of 16. Numbers are increasing as some with long COVID are reported to be developing a post-viral condition that meets the criteria for ME/CFS. Many of those are commenting on social media how they are experiencing similar disbelief and poor care from GPs as that which people with ME/CFS have been experiencing.

NICE lists problems with healthcare provision

In the ME/CFS guideline ng206 NICE acknowledges both in the guideline and in the Rationale section that there were 'common themes' [in the evidence they received](#) during the revision process for the guideline, which was finally published on 29th October 2021:

- a lack of belief about ME/CFS as a real condition by health and social care professionals
- a lack of understanding about what it is and the disabling impact it has, especially for the severely affected, including its fluctuating nature
- how experiencing a lack of understanding and prejudice can lead to people losing trust in health and social care services, including with children
- people with ME/CFS have negative experiences of healthcare services if they decline treatments that have been offered to them, especially relating to children
- one of the barriers to good ME/CFS management was a late diagnosis and a lack of monitoring
- people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect. Although safeguarding is not solely about children and young people, most of the concerns about its practice related to children and young people with ME/CFS
- people with ME/CFS have difficulties accessing services: physical accessibility; time constraints of appointments; sensitivities e.g. to light and sound; being discharged when missing appointments because symptoms worsen; few home visits for the severely affected; lack of suitable hospital care
- a lack of support with education and training for children and young people with ME/CFS
- a lack of access to multidisciplinary care and [unequal access](#) to teams with specialist knowledge of ME/CFS across England and Wales
- lack of access to support to develop an energy management plan (helps patients to plan rest and activity)
- harm reported from unstructured physical activity and inflexible exercise therapy designed to treat deconditioning
- lack of awareness of Orthostatic Intolerance, a common co-morbid condition
- harm has been caused when CBT is used as a cure for harmful beliefs
- regular follow ups or reviews are not commonly offered
- up-to-date training is not available to most health and social care professionals
- lack of specialist dietary advice, especially for the severely affected

Key NICE recommendations

The NICE [press release](#) outlines the key points in the guideline:

- diagnostic criteria: debilitating fatigue that is worsened by activity; post-exertional malaise; unrefreshing sleep or sleep disturbance; and cognitive difficulties ('brain fog')
- diagnosis should be made if symptoms have lasted 3 months or more
- people with ME/CFS should receive individually tailored support

- a personalised management plan should include areas such as energy management - including the importance of rest and staying within the individual's energy limits - the treatment of specific symptoms, and guidance on managing flares and exacerbations.
- people with ME/CFS should be directed to a ME/CFS specialist team (in the case of children this should be a paediatric specialist team) experienced and trained in the management of ME/CFS to confirm their diagnosis
- any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET), should not be offered for the treatment of ME/CFS.
- cognitive behavioural therapy (CBT) is not a cure for ME/CFS, and should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.

Mixed support from health professionals for the new guideline

The revised guideline has made significant changes to the 2007 guideline which doctors in the ME community hail as '[a triumph of science over discrimination](#)'. Others, such as physiotherapists have also produced [statements](#) indicating they intend to follow the guideline. Doctors' leaders, on the other hand, have [published a statement](#) accepting ME/CFS is a '*chronic, poorly understood condition and can be highly disabling and distressing*' but it also emphasised how they disagree with the guideline recommendations and the research evidence underlying them.

'The published guideline contains some positive changes, but these do not go as far as we would have liked and understate the importance of activity and exercise in the management of ME/CFS and the connection between people's mental and physical health.'

The statement says they are happy to change their terminology, but not bring their practice into line with the guideline:

'the personalised paced exercise programmes that are currently used in the NHS and termed GET. These have provided benefit to many patients and should not be discontinued. However, we recognise that the phrase GET is unhelpful and this terminology should be dropped to allow clinicians to work with their patients in a more productive way.'

Patients and carers are relieved and cautiously hopeful

Patients and carers mostly view the new guideline as 'a historical turning point' '*a big step in the right direction*' '*a foundation for hope*', but considerable caution has been expressed as well: '*it marks only the beginning of the transformation needed*'. It is also seen by some as

'only able to attempt to undo the damage done by inaction, ignorance, apathy and negligence during the past 14 years... it stands as a testament to 14 years of nothing much changing for people with ME, 14 years of failure from governments and establishment healthcare and research organisations in treating this disease.'

While hoping the new guideline will be a stepping stone for real change and the development of an ME-friendly health service, families affected by ME/CFS are now concerned that a guideline that is publicly not supported by some doctors' associations and chronic fatigue clinicians will be a 'white elephant' and patients will continue to be ignored and sometimes mistreated.

The big questions for all families affected by ME/CFS in Wales are:

Will the new NICE guideline make any difference to healthcare for people with ME/CFS?

Will NHS commissioners and doctors' leaders acknowledge the warnings of poor care and harmful treatments and actively work to eliminate them?

Will GPs consult the guideline and allow it to improve their ability to diagnosis and care for their patients?

Will training following the 2021 guideline and carried out by practitioners who understand ME/CFS be available for doctors and other health practitioners?

Will Health Boards provide the recommended management help and specialist services or simply rename the few existing services which currently accept people with ME/CFS?

Will training about ME only be available to professionals specialising in ME/CFS or will all professionals with ME/CFS patients have access to it?

Will parents of children with ME/CFS still be at risk from accusations of abuse?

Will patients and carers be listened to?

Conclusion – no delay, implement today!

In 2019 WAMES [reported](#) there was a “health and social care crisis” – even a “humanitarian crisis” for people with ME in Wales. We have seen little improvement since then. The 2007 NICE CFS/ME Guideline did not, on the whole, improve diagnosis and management of people with ME/CFS, in fact treatment recommendations led to years of worsening symptoms for some. NICE has confirmed that they also have received reports of ongoing neglect, prejudice, wrongful accusations of abuse against carers, and treatments that harm.

In 2021 we now have a guideline that demonstrates that ME/CFS is a condition which is possible to diagnose and that there are low-cost management strategies that all patients could benefit from. Some changes will cost money, but in the [Rationale and Impact section](#) NICE says:

for equity reasons, people with ME/CFS need the same access to healthcare and support as other NHS patients that is commensurate with the severity of their illness.

NICE also mentions that even where there are cost implications in improving healthcare the goals of helping people to ‘maintain or improve their health’, ‘reduce the number with deteriorating symptoms’ and ‘minimise the number of people who progress to severe ME/CFS’ would make the changes ‘highly cost effective’.

WAMES is therefore asking the NHS and health professionals in Wales not to delay any longer:

- **follow the science**
- **listen to patients and carers**
- **begin the process of developing a safe, empathetic and equitable healthcare service for people with ME/CFS.**
- **no delay – begin to implement the 2021 NICE ME/CFS guideline today!**