NICE Guideline – A New Chapter in The History of ME begins today, ~~18th August~~ 29th October!

After a fight lasting 14 years – and then an extra 2 months that came somewhat out of leftfield! - ME patients and advocates have finally had their exhausting efforts rewarded with sweeping changes to a clinical guideline widely deemed harmful by those subject to it. NICE, the body that the NHS and other healthcare services around the world take their clinical guidance from, today replaces its 2007-issued guideline that draws heavily on the recommendations of the discredited PACE Trial with completely overhauled guidance specifically ruling out GET (Graded Exercise Therapy) as a treatment.

In a process that has taken 4 years from the time the planned revision was announced, other recommendations have also been axed, management guidance added, and notes to clinicians regarding the very serious effect the disease can have on patients have also made a welcome appearance.

Here GMEG presents you with the key points from the guideline that we had hoped to bring you in our last newsletter, but which was derailed by a last squeak objection from the medical Royal Colleges that caused NICE to pause publication and take stock. The objection, which was over NICE's evidence assessment process around GET, was strongly and formally rebutted by NICE at a roundtable of stakeholders on October 18th and publication committed to. Which brings us to today!

We hope you find this summary of the new guidance useful and wish you the best from all the team at GMEG.

So, What Has Changed?

The use of CBT has now been downgraded from treatment to symptom management tool, reflecting the acknowledgement that ME patients are not curable with psychological therapies. Similarly, the Lightning Process is now specifically advised against in all forms, as are medicines and dietary supplements when offered as a cure. GET has been thrown out altogether and energy management inserted in its place with the directive "not to use more energy than [patients] perceive they have − they should manage their daily activity and not 'push through' their symptoms".

Patient-centred management is now at the heart of the recommendations, with diagnosis and care anticipated to be provided by new specialist clinics that offer at least once-yearly reviews of management plans (or every 6 months for children and young people). Clinicians are directed to offer a variety of means for conducting appointments, reflecting the challenges patients may face in attending in person, and are reminded that, even then, they will likely not be seeing patients at their worst; the common needs for physical accessibility and low-intensity sensory environment are also to be taken into account during both clinical appointments and hospital stays. Patients are not to be punished in any way or removed from the system for refusing any aspect of care.

Severe and under-18 sufferers now have guideline sections devoted to their more specific needs, which also expand on the better and swifter access to educational, employment and social support promised to all sufferers. The introduction of clinician responsibility in offering to liase with these services on behalf of the patient, along with immediate procurement by them of aids and adaptations, will make an especially big difference to these sections of our community. It is also hoped that the newly-introduced section on correctly identifying neglect and abuse in these two groups will reduce the number of appalling unjustified proceedings against parents and carers.

Many sufferers will also find it cathartic that there is specific acknowledgement of previous stigma and disbelief from health services, along with possible experience of harmful treatment approaches, creating a loss of trust from patients.

What’s Been the Reaction?

Pre-release copies of the new guideline have been circulated to ME charities and advocates, to an overwhelmingly positive response.

Forward-ME, which is an alliance of UK ME charities, support groups and health professionals, has welcomed the “major improvements”, saying it hopes the new guideline “will lead to improved healthcare provision and better relations between healthcare professionals and people with ME,” and “will signal a change in some attitudes, just as there has been for diseases such as epilepsy, MS, diabetes, and Parkinson’s in the past.” The statement goes on to say that “The guideline represents a new chapter in the history of ME. There is no place for those who perpetuated the stigma and misunderstanding that has caused so many people to suffer.”

Forward-ME founder Margaret, Countess of Mar, a leading ME advocate in the Westminster Parliament until her retirement, commented: “The scrapping of Graded Exercise Therapy as treatment for ME is a major victory for everyone with the illness. For years, patients have been telling the charities that the use of GET, with its goal-setting challenges, has plunged them back into ill-health. We so welcome the new sensible guidance on activity and energy management, with patients being allowed time for their bodies to help to heal themselves. It’s long overdue.”

Adam Lowe, one of the five patient representatives who had input on the guideline as a member of the NICE committee, has also expressed his joy and relief at the improvement in clinical care the changes will bring. "Some people will read the removal of GET as a net loss for clinics. But that's just not true. Time and time again, we heard from clinics that they felt hamstrung by the old guidelines, which only allowed them to offer two treatments - CBT and GET, perhaps with activity management as a neutral third option. If they tried to do anything else, they often wouldn't receive funding. Patients who didn't want these treatments were discharged without any further help. Now clinics can push for a broader range of skills in their team, such as dietitians, consultant physicians, specialist nurses, and experts in orthostatic intolerance, sleep, pain and migraines. With patients having regular review and monitoring, clinicians will have an expanded role. Clinics should be better resourced and more in tune with what patients want, which is a win for everybody."

Not all the NICE committee members were as happy with the outcome, however. Three of the twenty-one members resigned upon finalisation of the guidance, each of them associated with Biopsychosocial Model and GET/CBT proponent Esther Crawley. Two of the resignations came from Michael Beadsworth and Gabrielle Murphy - executive member and current Chair, respectively, of BACME, an organisation previously chaired by Crawley whose membership is supportive of the new anti-GET guideline (as shown by internal survey) but whose leadership partially clings to using GET and CBT. The third came from Joanne Bond-Kendall, lead physiotherapist for Crawley's MAGENTA and FITNET-NHS trials of GET on adolescents. Their refusal to lend assent to the new guideline may be taken as an indication of just how unfriendly towards GET the changes are.

Any Down Sides?

Stakeholders have expressed disappointment that the guideline doesn’t acknowledge the WHO’s and SNOMED-CT’s definition of ME as a neurological condition, instead referring to it as a “multi-system medical condition” – a term that doesn’t absolutely exclude psychological illness as a root cause. “These classifications are important,” says Forward-ME, “not only legally to healthcare providers to ensure correct implementation of the protocols, but also to people who have ME because it helps to validate the illness, encourage medical awareness and reduce the stigma that is still experienced.”

There’s also some consternation at the watering down of the guidance on exercise programs compared with the draft guideline. Whilst GET is still expressly excluded, along with any exercise program based on fixed incremental increases in physical activity, the wording concerning other exercise programmes now reads “Do not offer…any therapy based on physical activity or exercise as a cure for ME/CFS” in contrast with the draft’s “…as a treatment or cure...” The allowing of ‘exercise programmes’ as non-curative therapies with no description of what they could involve potentially leaves a loophole for exercise therapies that could push patients too far and too fast. Programmes using the title of ‘Graded Activity’ have already begun to spring up in clinics in response to the anticipated fall of GET, so this area will have to be watched intently.

Some are also unhappy that the draft of the guideline was more empatically restrictive on the utility of CBT than the final guidance, changing from “Only offer cognitive behavioural therapy (CBT) to people with ME/CFS who would like to use it to support them in managing their symptoms of ME/CFS and to reduce the psychological distress associated with having a chronic illness. **Do not offer CBT as a treatment or cure for ME/CFS**.” to “Discuss cognitive behavioural therapy (CBT) with adults, children and young people with ME/CFS (and their parents or carers, as appropriate). Explain its principles, including that it may help them manage their symptoms but it is not curative.” (Bolding is GMEG’s.)

What are the Next Steps?

The possibility of a judicial review of the guideline remains open to any party unhappy with the overhaul, though this is seen to be very unlikely to succeed.

The main focus now is to make clinicians aware of the change in guidance, since guideline updates are not routinely flagged to them but rely on a variety of routes – such as GP newsletters – to reach the retinas of health care professionals.

“While the guideline is a great improvement on the old one,” comments the Countess of Mar, “much still remains [to] be done to improve care for ME patients and the charity sector is very keen to be involved in the development of new clinical services. But we now need to know what action the Government are planning, and what funding will be made available, in order to make sure the recommendations percolate through to working practice.”

Can I Get Involved?

Charities are currently formulating various campaigns for circulating information to GPs and other clinicians, many of which will be helped by the involvement of patients so we will let you know about these!

There will also be a community Q&A session with two NICE guideline committee members: Caroline Kingdon, who is a Research Nurse at the London School of Hygiene and Tropical Medicine and has extensive clinical experience of ME, and Adam Lowe, one of five hard-working patient representatives who lent his energy to give a voice to sufferers.

Caroline and Adam spent almost 3 years working on this guideline so they are well placed to answer any questions you’d like to send their way on how the guideline was developed, what it means for sufferers, and what their views are on the recommendations that have been made.

A date and more details to come at a later time.