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A BRIGHT NEW CHAPTER IN THE HISTORY OF ME

Britain's ME charities said the publication today of a new NICE guideline on the illness has given the medical community a chance to reshape its troubled history.

“For too many years, sufferers have been relegated to the side-lines of medical care by being told that their illness is “all in the mind”.

“The new NICE guideline on ME/CFS, published today, gives doctors a chance to change all that,” said Forward-ME, an alliance of the country's main ME* charities, support groups and health professionals.

“The guideline turns a new chapter in the history of ME. It emphatically states that Myalgic Encephalomyelitis, is a complex and often long-term MEDICAL disease albeit with causes that are still being investigated.

“People with ME should now be able to access the whole range of health professionals in our incredible NHS to learn about effective forms of management and maybe, one day, a successful and safe treatment.”

An estimated 260,000 children, young people and adults in the UK suffer with this multi-system illness – with many no longer maintaining any contact with their doctors after being told that all the NHS can offer is cognitive behaviour therapy (CBT) and graded exercise therapy (GET).

Forward-ME said the new guideline contains major improvements to the prior version, published in 2007. In particular, members welcomed the abandoning of GET as a frontline treatment. Founder Forward-ME chairman Margaret, Countess of Mar, a leading ME advocate in the Westminster Parliament until her retirement in 2020, commented:

“The abandoning of graded exercise therapy as treatment for ME is a major achievement 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 welcome the new and sensible guidance on activity and energy management, with patients being allowed time for their bodies to heal themselves. It's long overdue.

“There’s also now very clear guidance that healthcare professionals should recognise the special needs of children and young people, and those with severe ME – who are often left with no medical care at all.

“Home visits by doctors are vital for the severely affected. Improved guidance on education including online education is welcomed. We hope this will lead to a reduction in the number of cases of parents being accused of psychologically harming their own children.”

The Countess added: “While the guideline is a great improvement on the previous one, 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 with a fresh approach. But we now need to know what action the Government are planning, and what funding will be made available, to ensure the recommendations percolate through to working practice.”

Forward-ME also has some concerns including that:

- The initial recommendation in the draft was that cognitive behaviour therapy should not be used as a treatment or cure for ME, it appears to have been watered down by repeating that it is not curative but offering treatment advice after pressure from some stakeholders and members of the guideline development committee.
- The fact that ME is classified as a neurological disease by the World Health Organisation, SNOMED and NHS Digital is not mentioned until page 81 of the guideline – this important recognition provides a passport to other NHS services it needs to appear at the beginning of the first main section.
- The guideline fails to recommend that specialist ME services in the NHS should be led by physicians – so these referral services could still lack meaningful medical input.

Forward-ME added: “This is a chance to turn that new chapter together. Patients and their families are not asking for special treatment – just that parity of respect and care already enjoyed by other service-users within the NHS.”

*Forward-ME agreed that chronic fatigue syndrome (CFS) fails adequately to describe the severity of the disease and should no longer be associated with ME therefore we use the term “ME” except when referring to the guideline or other published document which uses alternative terminology.

FOR FURTHER INFORMATION PLEASE SEE THE FORWARD-ME STATEMENT ATTACHED.