

Dear Editor,

The recent publication of a new NICE Guideline<sup>1</sup>, an All-Party Parliamentary Group Report (APPG)<sup>2</sup>, and new Research Priorities<sup>3</sup> heralds a dramatic shift in approaches and attitudes to Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) in the UK.

Largely ignored in all three publications, however, are unpaid carers (known outside the UK as family carers or caregivers). The vast majority of people with ME/CFS rely on their families for care and many of those families have been the driving force behind the changes to research and treatment that are now unfolding.

There has been limited research on unpaid care in the specific context of ME/CFS, but the few existing studies clearly show that the usual toll of caring for a sick or disabled family member is compounded by the historic prejudice surrounding ME/CFS and the absence of evidence-based treatments<sup>e.g.4-7</sup>.

While we applaud the commitment of NICE, the APPG, and the Priority Setting Partnership, it may still be decades before biomedical breakthroughs are made or translated into effective, widely available treatments for ME/CFS<sup>8</sup>. In the meantime, families will continue to provide the majority of care for people with ME/CFS and bear the physical, psychological, and economic scars of doing so.

The new NICE guideline *does* recommend support for carers, but the supports it recommends are generic. They will do little to address the unique needs of ME/CFS carers or their systemic mistreatment by health and social care professionals.

A change in the UK's approach to ME/CFS is long overdue, but without a focus on unpaid carers the puzzle will always be missing a piece. The wellbeing of carers must *also* be a priority in ME/CFS research and effective strategies must be developed to address their needs, and recognise and respect their expertise, in clinical practice and social care.

Kind regards,

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