

Prioritising Unpaid Carers in New Approaches to ME/CFS

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KEY FACTS

Policy area: Health and Social Care.

Aim: To understand the ME/CFS journey for unpaid carers, focusing particularly on unmet needs and directions for future research, policy and practice.

Approach: In-depth consultations with 20 people, from across the UK, providing unpaid care for family members or friends with ME/CFS.

Stage: Completed.

Background

In the UK more than 250,000 people have Myalgic Encephalomyelitis / Chronic Fatigue Syndrome¹, a devastating illness that is estimated to cost the British economy £3.3 billion per year². ME/CFS – which is characterised by extreme fatigue, pain, and cognitive impairment – has long been maligned as a psychological illness and treated accordingly. In recent years, research on the biological mechanisms of ME/CFS has advanced, prompting a dramatic shift in approaches to treatment and priorities for research.

In the UK, a new NICE guideline¹ has encouraged a shift away from psychological and behavioural treatments, while a research prioritisation process³ has encouraged a focus on biological mechanisms, diagnostic tests, and the development of medical treatments. In addition, a 2022 All-Party Parliamentary Group (APPG) report⁴ has outlined clear expectations of, and support for, a transformation in the way ME/CFS is addressed in research, policy, and health and social care.

Although these are welcome changes, one important group has been largely ignored: unpaid carers. This is despite the fact that the 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 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 prejudice surrounding ME/CFS and the absence of evidence-based treatment⁵⁻¹¹.

In 2021 our team, funded by GW4, conducted a series of consultations with people caring for family members with ME/CFS. We sought to understand their needs and experiences, in order to make recommendations for better supporting carers in ME/CFS research, policy, and health and social care.

Key Observations from our Consultations

- Caring for a family member with ME/CFS is often a **full-time role** and can include (but is certainly not limited to): providing emotional support; providing physical assistance (including lifting, washing, and toileting); managing symptoms and medications; coordinating appointments and liaising with professionals across health, social care, welfare, and education; managing finances; and advocacy at all levels.
- Caring for a family member with ME/CFS is characterised by **uncertainty, isolation, and devastation**.
- Widespread stigma and misunderstanding about the condition leaves carers isolated from friends and family, **abandoned by health and social care professionals**, and facing a constant battle to access information and appropriate support for the person with ME/CFS.
- Many carers have been **traumatised by the experience**, particularly those who have been accused by health and social care professionals of fabricating or inducing the illness, neglecting the care recipient, being adversarial in appointments, or failing to administer treatments properly. While positive encounters with supportive professionals have been reported, they are the exception.
- In prioritising the needs of the person for whom they care, carers have seen their own physical health, mental health, relationships, and financial security destroyed. Some carers have even **contemplated suicide**.
- Older carers fear for the future and describe a “race against time” to improve the health of the care recipient (or make other care arrangements) before their own death.
- Carers who can afford private medical and allied health services say professionals in the private sector are more compassionate and better informed than those in the NHS.
- Carers say they have become ‘**experts by experience**’ – keeping up-to-date with the latest research findings and proposed treatments, learning (by trial and error) the best ways to manage ME/CFS symptoms, connecting with other carers to find out about resources and support services, and educating health and social care professionals. But this expertise has been borne of necessity, not desire. Carers say they wouldn’t have to be experts if health and social care professionals took ME/CFS seriously.

Policy Recommendations

The recent change in attitudes to ME/CFS is a welcome one, but it may still be decades before biomedical breakthroughs are made or translated into effective, widely available treatments¹². In the meantime, family carers will continue to provide the majority of care and support for people with ME/CFS, at great cost to their own wellbeing. There is an urgent need to ensure that – in research, policy, and health and social care – carers’ needs, experiences, and expertise are being fully recognised and appropriately addressed.

While the new NICE Guideline and the APPG report go some way to encouraging greater respect for and inclusion of carers, they do not go far enough. They provide little in the way of practical guidance for health and social care professionals seeking to work in genuine partnership with carers. They also suggest referring carers to generic information and support, a strategy that will do little to address the unique needs (or historic mistreatment) of ME/CFS carers and that has, in an under-resourced system, been of little benefit to carers more generally¹³⁻¹⁶.

Consequently, there is an urgent need to:

- Acknowledge the significant harm that has been done to carers by a health and social care system that has misunderstood and mistreated people with ME/CFS.
- Ensure carers' voices are included in all policy making about ME/CFS.
- Recognise carers as experts by experience and vital advocates, particularly for those with severe ME/CFS who may be unable to advocate for themselves.
- Ensure health and social care professionals are equipped with the skills and resources to engage in positive working relationships with carers.
- Ensure that the wellbeing of ME/CFS carers is a priority in health and social care provision.
- Ensure that the wellbeing of carers is a priority for ME/CFS research.



Contact Details

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