Cymdeithas
Cefnogi
ME & CFS Cymru

WAMES

Welsh Association
of ME & CFS
Support

WAMES' Vision for ME/CFS Healthcare in Wales 2026/27

An all Wales strategy

- to improve training for diagnosis and management
- to develop a healthcare pathway
- shaped by NICE for ***all ages*** and ***all severities***
- to consistently record diagnoses to give accurate statistics
- co-produced to ensure it relates to patients' needs
- to safeguard patients when accessing non-ME services
- recognising the role of the whole family, not just the person living with the condition

⚠️ Without a coordinated strategy, vulnerable patients are left without adequate support across Wales

Only 3 of the 7 services cater for children and young people: Aneurin Bevan; Hywel Dda; Swansea Bay

Only 3 of the 7 services cater for the severely and very severely affected: Aneurin Bevan; Hywel Dda; Swansea Bay

Services that are

- for all ages and severities
- shaped by the NICE 2021 guideline
- developed through true co-production with patients, carers and third sector
- truly suitable for people living with PEM/PESE the key characteristic that makes ME/CFS different to most other conditions

NICE recommends

Learning energy management and pacing to minimise exacerbating any or all symptoms

Co-production A way stakeholders can work together in an equal partnership to produce services that better fit the needs of the people they serve, making them more accessible and relatable

The risk without training

Clinics and hospitals can make people with ME/CFS, especially the severe and very severe worse, without training in ME/CFS care.

> *'Lack of appropriate health care and support has, and is, affecting my life chances. I feel invisible to the world.'*
>
> **— MP (person with ME)**

Healthcare settings must understand PEM to avoid causing serious harm to patients

PEM (Post-Exertional Malaise)
Worsening of symptoms following even minor physical or mental exertion, with symptoms typically delayed by hours or days

Our Journey and the Growing Need

Since 2000 WAMES has been asking for access to appropriate healthcare. We've not been asking for anything special, just parity with other medical conditions - respectful treatment from informed professionals.

In 2023 NHS Wales began to take some steps towards easing the battle for healthcare - the new Adferiad services for people with long COVID were opened up to some, but not all, people with ME/CFS. In 2025 NHS Wales Performance and Improvement began an ME/CFS 'discovery project' with no timetable and undefined goals.

The scale of the need has multiplied and now, post COVID, there are an estimated **18,986 people** with ME/CFS in Wales, many without a confirmed diagnosis and support. Approximately **50% of Long Covid patients** meet the ME/CFS criteria meaning numbers with ME/CFS will be much greater.

Contact: Jan Russell | jan@wames.org.uk | www.wames.org.uk
Advocacy and Campaigns Coordinator / Chair
Welsh Association of ME & CFS Support