

NNDM8884 - Member Debates

Tabled on 24/04/2025

To propose that the Senedd:

1. Notes that myalgic encephalomyelitis (ME) is a chronic and disabling illness at all levels of severity.
2. Notes that of those suffering from ME, 25 per cent are categorised by NICE as 'severe: mainly bed bound or housebound', and 'very severe: fully bedbound', requiring full-time care and, in the severest cases, palliative care and tube feeding.
3. Regrets that it is often those with the greatest severity levels of ME who are provided with the least amount of appropriate care and treatment.
4. Calls on the Welsh Government to:
 - a) respond to the concerns raised in the Coroner in England's Prevention of Future Deaths Report, and explain what practical steps they will take to ensure that no patient in Wales will ever be placed in such tragic circumstances as those described in the report;
 - b) ensure that the Adferiad-funded ME services are making provision appropriate to the needs of patients with severe and very severe ME;
 - c) bring together an expert group of health professionals and people with lived experience, at a national level, to develop all-Wales guidance and quality standards on ME, including for the most severely affected;
 - d) make the appointment of an all-Wales specialist consultant for post-infectious chronic conditions - including ME and long COVID - a priority;
 - e) improve the training on ME for professionals, firstly in the NHS, but also in social services and schools: in particular, raising awareness of the care needs of adults and children with severe and very severe ME; and
 - f) ensure that health boards truly co-produce their ME and long COVID Adferiad services, taking into account the lived experiences of those suffering at the severest levels and of those caring for them.