

M.E. matters now: Wales manifesto 2016

M.E. (Myalgic Encephalomyelitis) is a chronic, neurological illness affecting 12,000 adults and children in Wales. This is more than the number of people known to have Parkinson's disease and MS combined.

Despite this, the majority of people with M.E. in Wales have no access to specialist healthcare, struggle without social care and are often stigmatised and isolated because of widespread misconceptions about M.E.

"M.E. has affected everything I do. I can't have conversations with anyone anymore as I can't concentrate. I can't leave my home alone and I constantly have severe pain in my arms and legs. My family get frustrated with me because I can't do anything. My partner doesn't believe me and thinks I'm lazy." 26-year old with M.E. in Flintshire

Time for change

Following the publication of the 2014 report¹ by the M.E./CFS and Fibromyalgia Task and Finish Group, foundations have been laid for improved healthcare for people with M.E. in Wales. The All Wales ME-CFS and Fibromyalgia Implementation Group has been established to oversee delivery of the report's recommendations to support timely diagnosis and effective management of the condition.

Local Health Boards in Wales have been asked to improve services by:

- nominating an executive board member and a clinical lead to take forward recommendations
- forming local multi-disciplinary stakeholder groups to develop effective care pathways, raise awareness of M.E., increase timely diagnosis and share good practice
- preparing three-year action plans setting out how they will deliver services to meet the needs of their population.

What can Assembly Members do?

You can make a difference by:

- understanding key facts about M.E. and its impact on those affected
- scrutinising the ongoing implementation of the Task and Finish Group's recommendations to transform healthcare for people with M.E.
- supporting access to appropriate social care and a fair and effective welfare benefits system for people with M.E. and their carers
- supporting provision of appropriate support for people with M.E. who are able to access education, employment and training opportunities.



Every person with M.E. – wherever they live – should have access to informed support. Will you help build on the foundations laid by policy-makers and campaigners in Wales to end the unfairness and transform the lives of people with M.E. and their families?

Challenges faced by people with M.E. in Wales

Around a quarter of people with M.E. are severely affected. This means that they are house and/or bed bound, unable to perform even the most basic tasks for themselves.

"There is a need to meet the intensive and specialist care needs of the small numbers of people who need inpatient care or palliative care, and the larger group who may need to access domiciliary care."²

Even for those less severely affected, M.E. has a significant impact.

"M.E. has meant major life changes, such as part-time working from home, no career development, very little recreation and social life, and missing out on many aspects of family life. It's had a big effect on the whole family, but especially my wife being my carer, with the worry that entails."

M in Powys, diagnosed in 2000

Research³ indicates that a "good relationship with the GP from the outset of the illness is very important in achieving a good outcome and avoiding severe illness."

But Action for M.E.'s 2014 survey⁴ found that, in the past year, nearly one in three people with M.E. in Wales hadn't seen their GP at all.

For those who do access their GP, there are almost no specialist services available.

"My GP has always helped and has learned about M.E. The lack of time he is allotted for each patient is a drawback. I think the absence of facilities in Wales frustrates him." M.E. patient, Powys

88% of people with M.E. in Wales who responded to Action for M.E.'s survey told us they had had to stop or reduce paid work.⁵

"I have had to give up a well-paid career and my husband lost his job because he had to care for me. I have two grandchildren and cannot spend as much time with them as I want to, or have them to stay over. I have not been able to visit my daughter or elderly father-in-law, who live in England."

Woman with M.E. in Swansea

81% of people with M.E. in Wales told Action for M.E. that they had not had a social care assessment in the past five years⁶ and rely on family or friends for support with the most basic day-to-day activities.

"My mum picks up a huge burden because I now live back at home with her and my dad. She shops and cooks for me, on top of running the household and working in a demanding job. She can't retire yet and has to carry on despite having a long-term condition herself. I'm in my thirties. She shouldn't have to still have to care for me at this age."

Woman with M.E. in South Wales

M.E. matters now: we are asking Assembly Members and candidates to pledge their support for this manifesto by contacting Action for M.E. on 0117 927 6622 or emailing policy@actionforme.org.uk



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References

1 M.E./CFS and Fibromyalgia Task and Finish Group (2014) *Report and recommendations*

2 *ibid*

3 Pheby, D. and Saffron, L. (2009) Risk factors for severe M.E./CFS. *Biology and Medicine*, 1(4), p 50-7

4 Action for M.E. (2014) *M.E. time to deliver survey report*

5 Findings from Action for M.E.'s 2014 *M.E. time to deliver* UK survey of more than 2,000 people with M.E.

6 *ibid*

Anonymised quotations from people with M.E. have been sourced from responses to Action for M.E.'s surveys and consultations.