



M.E. matters now: Scotland Manifesto 2016

M.E. (Myalgic Encephalomyelitis) is a chronic, neurological illness affecting 21,000 adults and children in Scotland. 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 Scotland have no access to specialist healthcare and are often stigmatised because of widespread misconceptions about M.E. Many feel isolated, abandoned and dependent upon family or friends to survive.

"I want to work, I wish I could, but without expert help I stand no chance at all." James, who has M.E.

What are our goals?

- Training for all professionals providing health, care and support services to people affected by M.E., linked to the establishment of a national professional network.
- Access to a fair and effective welfare system that meets the needs of people with chronic fluctuating and cumulative symptoms.
- Timely and informed support to help those people with M.E. who have capacity to access employment, education or training opportunities.
- All carers have access to timely, holistic support and that their needs are routinely considered by health and care professionals.
- Every person living with M.E. – including the most severely affected – has access to a person-centred care plan including ongoing monitoring and support, and specialist diagnostic and condition management services.

"I have an incurable cancer, but my long-term M.E. is much worse and my main problem. However, whenever I see any doctor, M.E. is completely ignored. I'm left to deal with it myself." D, Edinburgh.

Did you know M.E...

- can be as disabling as MS or congestive heart failure?¹
- is the main cause of long term school absence?²
- costs the Scottish economy approximately £9 million a year in lost earnings?³

Since 2002, there has been extensive consultation¹ with M.E. patients, carers and supporting charities, resulting in:

- 9 recommendations for M.E./CFS services sent to NHS Boards⁴
- 9 priority areas for action in policy, welfare benefits, healthcare and research⁵
- 26 recommendations for national, regional and NHS Board actions⁶

It's 2016, 14 years on, and we know what's needed.

Now it's time for action.

What can the Government do?

Modest investments in professional training, integrated care planning and specialist support⁷ could:

- transform the lives of 21,000 individuals and families affected by M.E.
- save public money through more effective use of scarce resources
- benefit patients with other conditions by reducing inappropriate referrals to clinics that do not have the expertise to provide relevant support for M.E.
- benefit communities through enabling people with M.E. to fulfil their potential to contribute to society.

Pictured is Louise Wilkie in Newton Mearns, who has been ill with M.E. since 2011.

73% of adults with M.E. have had no contact with an M.E. specialist in the past five years⁸

“Apart from NHS referrals when I was first ill, no help whatsoever in managing M.E. after the diagnosis – no interest from GPs in [...] a serious chronic illness, 30 years on and still counting.” Maggie, Edinburgh Self-Help Group

93% of children and young people with M.E. felt their condition would be better understood if it were more visible⁹

“Only four out of 14 Health Boards in Scotland provide any sort of service. Considering there are around 21,000 already diagnosed in Scotland, that’s not good enough.” Ann, Highlands, whose daughter has M.E.

468 patients with M.E. symptoms were referred to the Fife NHS M.E. clinic between 2010 and 2014 and the referral rate is rising. The service supports up to 350 patients at a time.¹⁰ The clinic is praised by patients¹¹ and frequently receives requests from patients – often housebound – in other parts of Scotland, desperate for specialist support.

“My appointments [at the Fife clinic] ran for less than a year, maybe eight in total, gaining information on vitamins and supplements, effective use of pacing, positive thinking and living, support and practical advice with employment issues and understanding of inflammatory response/muscle weakness and fatigue – all of which have allowed me to get on with life. The benefits of these appointments will last a lifetime.” M.E. patient, Fife.



Every patient – wherever they live – should have access to informed support. Will you help us make this the first Scottish Parliament that ends the unfairness and transforms the lives of people with M.E. and their families?

Acknowledgements

This Manifesto has been produced collaboratively by:

- Action for M.E. Tel: 0117 927 9551. www.actionforme.org.uk
- Association of Young People with ME. Tel: 0330 221 1223. www.ayme.org.uk
- ME Association. Tel: 01280 818964. www.meassociation.org.uk

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References

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5. Scottish Parliament Cross Party Group on ME (2007) Legacy Paper
6. Scottish Public Health Network (2010) Health Care Needs Assessment of Services for people living with ME-CFS
7. *ibid*, Appendices 3 (Three Tier Service model) and 6 (Costs)
8. Action for M.E. (2014) *M.E. Time to Deliver* survey of more than 2,000 adults with M.E.
9. Association of Young People with ME (2015) Survey of 800 children and under 25's with ME
10. Data from NHS Fife's long-running ME/CFS service run by Scotland's only specialist ME nurse
11. www.patientopinion.org.uk