

M.E. matters now: Northern Ireland manifesto 2016

M.E. (Myalgic Encephalomyelitis) is a chronic, neurological illness affecting 7,000 adults and children in Northern Ireland. This is more than the number of people known to have Parkinson's disease and MS combined.

Despite this, there is no specialist healthcare provision for M.E. in Northern Ireland. Those affected by the condition are often stigmatised because of widespread misconceptions about M.E. Many feel isolated, abandoned and dependent upon family or friends to survive.

"For a number of years my daughter was, from the age of nine, my main carer while her dad was at work. My husband is now my main carer on top of a full-time job. There is still a lack of understanding about my condition amongst my extended family." Woman with M.E. in Derry

Time for change

Focused and determined engagement with MLAs and the Health and Social Care Board, undertaken by individuals and advocate groups, has already highlighted the desperate situation for people in M.E. living in Northern Ireland.

The Patient and Client Council and the Pain Alliance¹ are among those adding their support to M.E. groups calling for change.

Essential to improving outcomes are:

- raising awareness of M.E. among GPs to support timely diagnosis
- provision of specialist healthcare services offering evidence-based management of the condition.

What can the Northern Ireland Assembly do?

You can make a difference by:

- understanding key facts about M.E. and its impact on those affected
- scrutinising the Health and Social Care Board's commitment to improving outcomes for the 7,000 people in Northern Ireland living 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 M.E. campaigners in Northern Ireland to end the unfairness and transform the lives of people with M.E. and their families?

Challenges faced by people with M.E. in Northern Ireland

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

"I was very sporty, playing to a high level, but since 1993 I haven't been able to resume that. When I have tried I have had relapses. I also have limited social activities as they take so much out of me."

40-year old with M.E., County Antrim

Nearly 70% of people with M.E. in Northern Ireland who responded to Action for M.E.'s survey told us they had stopped or reduced paid work.²

"I had to give up my job. My family have taken over most household tasks. My mobility is now severely restricted and I use a mobility scooter outside of the house. I feel that I have not yet managed to prevent my illness from slowly progressing."

Former teacher with M.E.

88% of people with M.E. in Northern Ireland told Action for M.E. that they had not had a social care assessment in the past five years³ and rely on family or friends for support with the most basic day-to-day activities.

"I feel cut off from the world and depend greatly on my husband and two children. My family had never thought in a million years that they would be looking at future like this."

County Armagh, diagnosed with M.E. in 2008

Research⁴ 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."

Action for M.E.'s 2014 survey⁵ found that, in the past year, one in five people with M.E. in Northern Ireland hadn't seen their GP at all; while 61% felt their GP was poorly or very poorly informed about M.E.

*Speaking at a meeting in February 2016 at Stormont, Jo-Anne Dobson MLA said: "M.E. and fibromyalgia are among our most under-supported illnesses. That needs to change."*⁶

M.E. matters now: we are asking MLAs 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 www.hope4mefibroni.btck.co.uk/news
- 2 Findings from Action for M.E.'s 2014 M.E. time to deliver UK survey of more than 2,000 people with M.E.
- 3 *ibid*
- 4 Pheby, D. and Saffron, L. (2009) *Risk factors for severe M.E./CFS*. *Biology and Medicine*, 1(4), p 50-7
- 5 Action for M.E. (2014) M.E. time to deliver survey report
- 6 Event organised by www.hope4mefibroni.btck.co.uk
Anonymised quotations from people with M.E. have been sourced from responses to Action for M.E.'s surveys and consultations.

