

TEMPLATE LETTER TO YOUR NEW OR RE-ELECTED MP

Dear xxx

I have an illness known as M.E. – Myalgic Encephalopathy – which affects around 250,000 people in the UK. Children as well as adults are affected. This means there are around 400 other people in your constituency who also have ME – some of whom will have severe ME, meaning that they are housebound or even bed-bound.

Please could you spend a few minutes of your time to look at five key concerns that affect people with this illness and then consider how you can best assist with the formation of a new All Party Parliamentary Group on M.E. that can represent their interests and concerns. The APPG will need officers as well as members from all parties.

The five key concerns are:

1 DWP BENEFITS

Along with other fluctuating medical conditions, people with ME/CFS often have great difficulty in obtaining DWP sickness and disability benefits to which they should be entitled and are only able to do so after going to appeal.

2 MEDICAL EDUCATION

Many people with ME experience long delays, sometimes over a year, in obtaining a formal diagnosis. In the meantime, they are often given inadequate, or even inappropriate or harmful advice, on management. This is because medical education on both the diagnosis and management of ME/CFS at undergraduate and postgraduate level is sketchy or even non-existent.

3 MANAGEMENT

The 2007 NICE guideline on ME/CFS is no longer meeting the needs of people with ME and needs to be fully revised. This was confirmed by Professor Mark Baker from NICE when he spoke to a meeting of ME/CFS charities at the House of Lords in June 2014. However, the NICE guideline has been placed on the inactive 'static' list by NICE and there are no plans by NICE to make any revision.

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4 RESEARCH

Although the Medical Research Council has identified a list of high priority biomedical research items, funding for key areas of biomedical research – which also includes clinical trials of drug treatments and research infrastructure such as the M.E. Biobank at the Royal Free Hospital – still has to be largely funded by the charity sector.

5 NHS SERVICES

People with M.E. in many parts of the UK still do not have a local hospital-based specialist service to whom they can be referred by a GP for further advice on either diagnosis or management. For children and adolescents, the availability of specialist referral services is extremely patchy – despite ME/CFS being one of the commonest causes of long-term, sickness absence from school. For the 25% of people who have severe ME – being housebound or bed-bound – domiciliary services and in-patient facilities are extremely difficult to find if they exist at all.

Optional insert for comment on a specific local problem:

Here in xx ...

As you can see there are very real concerns about the way in which the Department of Health is dealing with an illness that affects around 250,000 people in the UK and which is costing the country an enormous amount of money in lost revenue through the prolonged ill-health and the disability it causes.

If you are interested in helping to set up a new APPG, please email the ME Association – one of the two national charities prepared to share duties in an unpaid secretariat. Their email is meconnect@meassociation.org.uk

Optional insert:

I would also like to discuss these concerns with you in person if you are able to do so.

I look forward to your response

Yours sincerely

xxxx