

House of Commons, Westminster, London SW1A 0AA

Dear

No Testing: No Results - No Care?

I am writing to you as constituent who is severely affected by the neuro-immune disorder myalgic encephalomyelitis. Sadly, this is one of the most unpleasant, debilitating, and long lasting of illnesses.

Some time ago, the 25% ME Group, UK charity for severe M.E. sufferers, shared this humorous parody:

Physicians who manifest the metaphysical belief system of "If we don't know about it, then it doesn't exist" are suffering from a mental defect or psychological condition known as "Doctors with Unexplained Medical Beliefs" or D.U.M.B.

Unfortunately this 'parody' is fast becoming an accurate reflection of professional attitudes, and not just among doctors. Some people with severe M.E. seeking help with basic care are being considered perfectly well and therefore in no need of support. Even when hungry, wet (through incontinence) and barely able to walk.

Although many biomedical abnormalities have been identified in the course of research on this illness, there remains little or no access to specialist testing on the NHS. This poses very real problems for patients, given the risk of encountering the mindset that no pathology can exist unless and until established in the individual patient by testing. People are suffering unnecessarily and desperately in need of help.

This mindset is feeding into a highly adversarial home care assessment process.

The watchword is 'Objective' – which unfortunately translates as highly depersonalised, de-humanising, rigid, suspicious, and mistrustful. A person's need for help can and will be denied, unless and until social services consider the need 'proven'. The 'proof' being sought by today's caring professionals? Test results. Sadly, the very professionals who have a 'duty of care' increasingly present further burdens and barriers. No testing, no results, no care.

How can you assist constituents with M.E.?

The 25% ME Group would welcome the opportunity to meet with you at a drop-in event for MPs, to be held Wednesday 11th May from 12.30 to 2.00. The venue is Room Q, Portcullis House, and lunch is provided. This event is hosted by the All-Party Parliamentary Group on M.E., which is currently launching an inquiry asking how people with M.E. can better access appropriate social care.

If you are unable to attend, perhaps you would be able to send along a representative?

You can also request for further information and/or provide your thoughts on the way forward by contacting the 25% ME Group directly. Details are below.

Yours sincerely,

Your Details

Your Request

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PLEASE RETURN TO: The 25% ME Group, 21 Church Street, Troon, Ayrshire KA10 6HT

or e-mail: enquiry@25megroup.org

MANY THANKS