



Invest in ME

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Questions from Invest in ME to Mike Penning, Minister of State for Disabled People Mike Penning

1/ It is clear from many of our supporters that GPs are often known to refuse referrals for their ME patients on the grounds that there is little point in doing so as they believe there are no treatments.

This illustrates an ignorance of ME and of research into the disease (RCGP Chair Dr Clare Gerada stated at the IIMEC8 Invest in ME International ME Conference, in London in 2013, that GPs know little about ME).

This impacts the patient as well as compromises their entitlement to benefits.

Some of the clinics set up for ME and CFS specifically state:

“Please note that we do not accept referrals where the sole purpose is for second opinion for pending benefits claims.” (- King’s College CFS Unit)

How are patients supposed to obtain medical evidence for their benefits applications if they are refused referrals and the few clinics set up to see these patients cannot provide appropriate support?

How are they supposed to get better if their personal physician is ignorant of the disease and refuses to facilitate the possibility of improved treatment?

This adds further stress for patients and their families and enforces again the view that ME patients are subject to systemic bias in the healthcare system and ignored by disabilities agencies.

Effectively ME patients are discriminated against.

2/ The failure of government policy on ME for a generation means that few patients have decent healthcare or prognosis once they have the diagnosis of ME.

This makes the impact of ATOS and welfare reforms even harder than usual for ME patients as no one seems to take responsibility for this group of patients even though many acknowledge the shameful treatment these patients have received (in Norway the government officially apologised for their treatment of ME patients).

How is it possible then for Atos medical assessors to be able to give prognoses of ME patients' ability to return to work based on one interview and with no knowledge of the disease and no understanding of the effects of the disease and especially the consequences from post-exertional malaise?

It is obvious from patient experiences that ATOS are acting purely to enforce DWP policy to deny benefits - seemingly influenced by the outdated establishment bias which has been allowed to be built up by vested interests.



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3/ The role of the ministry is to improve the health and safety system, simplifying the welfare system and making sure work pays. Helping people to find and stay in work.

It is plainly obvious that these objectives are completely failing in being materialised for ME patients.

We would respectfully suggest that the minister consider the following in relation to the ministry's objectives -

- The health and safety of patients has not been improved and continues to be so poor that severe deterioration and even deaths from ME are becoming more frequent.
- The welfare system for ME patients is a scandal - with little understanding of the disease being exhibited by DWP, or their contracted third-party organisations such as ATOS, and not even healthcare practitioners.
- Making sure work pays is a meaningless concept if people are denied any hope of development of treatments or cures for this disease due to lack of proper research being funded by those charged with that responsibility (such as the MRC).

The minister, we feel, should consider the deplorable state in which successive governments have left ME patients.

An entire section of the population is discriminated against on a regular basis - something a Minister for Disability Issues really ought to consider a major priority.

The Chairman and Board of Invest in ME

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