

**P-04-587 A dedicated Support Team for Myalgic Encephalomyelitis –
Correspondence from MESiG to the Clerking Team 12.01.15**

TASK AND FINISH REPORT RESPONSE

Comments from M.E. Support In Glamorgan (MESiG) - 10.1.15

Thank you for all the hard work that has gone into this report to date.

The Report sounds absolutely wonderful in theory but MESiG cannot see how it can be implemented as there are many obstacles.

At present many GPs struggle to even diagnose M.E. never mind make an increase in timely diagnosis. We are still hearing that people are being told that M.E. does not exist, that it is a psychosomatic psychological illness as opposed to a physical illness. This has to be addressed if patients have any chance of being treated correctly.

M.E. is defined by the World Health Organisation as a neurological condition, so it's encouraging to see that the Neurological Conditions Delivery Plan is referred to in the report (specifically in Recommendation 4) as forming the basis for developing effective local pathways for children and adults with ME/CFS and Fibromyalgia.

It is of concern however that despite ME being defined as a neurological condition, the Neurologists that we have come across say that ME is not a neurological condition.

Following from this, it's important that the clinical leads for ME/CFS and Fibromyalgia within each Local Health Board have experience of treating patients with neurological conditions. Can you tell us why so many psychologists are members of the Task and Finish group?

The urgent need for timely and appropriate healthcare for people with ME/CFS and Fibromyalgia cannot be overstated, particularly those who are most severely affected and house- and/or bed-bound.

For example: We are seeing one woman who is 4 stone 12 in weight, who lives alone, bed-bound, unable to look after herself, and is intolerant to light and sound. She is afraid to go to hospital as they don't cater for her needs. Her weight is dangerously low but there is nowhere for her to go for treatment, where her needs can be met. Another woman had her care stopped and was told that M.E. was in her mind. She is also bed-bound/housebound. There are too many cases like this and the clock is ticking for them. The woman who is 4 stone 12 will die if there is no intervention. We are highlighting this to show the need for urgent action. MESiG does what it can but mostly it is a case of keeping people with M.E. hopeful that things will improve, that someone, somewhere will do something to recognise their illness and provide suitable treatment for them.

MESiG committee members have a wealth of knowledge between them as they either have M.E., had M.E. or care for someone who suffers with it. The organisation has been supporting people with M.E. for 30 years, so has a vast experience of people's challenges with accessing appropriate help, support or diagnosis. We are happy to meet with anyone who would benefit from our experience. As you are aware, we are asking for a clinic, run by an ME specialist with an ME trained team. It's not too clear if this is what you are proposing in this report but fundamentally people just need to be diagnosed, believed and treated.

Too many people across Wales have waited too many years for suitable treatment, so that they are not held in illness year after year with no hope of improvement. Many with M.E. were previously successful people, caring for their families and with careers. They do not want to remain on benefits, dependent on others.

The time is right for correct action to be taken and for Wales to be a leader in the treatment of people whose lives have been blighted by this serious condition.