

PE1690/SS

Anonymous submission of 11 December 2019

Following the meeting on Jan 24th, with the stated intention by CMO to form a working group, and as part of my response to the consultation on the NAP I have been in phone and email contact with members of the Clinical Priorities team, to try and contribute my experience and opinions as an ME sufferer to the ongoing work. I am not affiliated with any particular group (although a member of Action for ME, I don't speak for them in any way.) and speak only as an individual.

I live in Glasgow, I am female, I have had ME for 33 years, since the age of 15. My story is typical of many. I got a lot worse in 2007, but even so would only be classed as Moderate, because I'm not lying in the dark unable to feed myself or sit up, or read. I am dependant on my 83 year old mother for my care day to day. I dislike the word Moderate as it has overtones of 'not too bad'. My frustration with my illness and the impact it has on my life is only growing. I have no-one to call about symptoms or treatments or any kind of support at all except my GP.

What tangible progress on research or care for people with ME has been made since January - none. If any patient contacts their GP there is nothing new at all. We are no closer to a diagnostic test, to treatment clinics, or any specialist care. Whose fault is that? The system. The NHS is great at emergencies, at saving lives, at treating known things - have x symptom, take y treatment, result = recovery. The NHS (throughout the UK) is spectacularly bad at caring for those of us with currently untreatable conditions. 'I don't know' is the honest answer to patient questions, all too often instead medical staff turn that back on the patient and make us feel like the problem. The system as it exists is not set up to work to fill in those don't knows with real answers. The strains on the system - staff shortages, tight funding, the sheer size and hierarchical nature of Health Boards means that change is so slow as to be undetectable to the public. And sometimes that covers up that there is resistance to change, that for example, Neurologists don't want us as patients. The responses the committee has received from the Health Boards are testament to that. ME patients are still not believed by many and are viewed as a nuisance.

What *is* going on, with staff in Clinical Priorities pulling as hard as they can on the ropes available to them, is more work to consult patients and come up with workable plans that Health Boards will accept. Trying to bring together the charities and patient groups to agree on specific points has been very time consuming. Partly because those groups contain people who are ill themselves, partly for lack of resources within those groups and partly from conflicting viewpoints. Add to that the challenges of dealing with a patient group that has no focus - no clinics, no patient lists, to even find us, and then that so many of us are too ill to participate in anything - the task of all this should not be underestimated.

I am incredibly frustrated with how slow things have been, and how little progress, overall has been made. But I don't feel that any one person, or dept can be held responsible for that. I do think the Health Boards - whosoever within the Health Boards with 'responsibility' for chronic illness in general and ME specifically - are a blockage. Hopefully the nature of the NAP framework will allow strong discussions to take place to change that.

Write a letter, wait for a response, meet again in x months - that is the system we have. Patients are ill all day every day, and it feels very much as if that is not recognised throughout the many levels of the overall system. We don't feel a sense of urgency for change, to relieve our suffering. Right down to the frontline services, most people aren't dying of this illness, so we must wait our turn. THIS is our turn.

The work on updating the Needs Assessment, producing Prevalence Data, and the Gathering Views exercise by SHC needs support - to find the patients. I would ask members of the committee to do everything they can to publicise this work, in their constituencies, through every other committee they sit on, anything, so that as many people as possible see that this small thing is happening - to give Scottish Government the mass response needed to prove the need for action at Health Board level. And if the committee shares my frustration at slow progress - understand the blockages and nature of the system and if you can, change that too!

Thank you for the committee's continued interest in ME care.