

PE1690/DD

Stuart Brown submission of 14 May 2019

Copy correspondence from Stuart Brown to the Cabinet Secretary for Health and Sport and the Chief Medical Officer, 14 May 2019

I refer to my letter of the 28th of February, which is copied out below for your convenience. I gratefully acknowledge that an official has replied to some of the issues raised in the letter. However, I'd be most obliged if you could reply to the outstanding items, *viz*:

- **The Government need to enquire urgently as to why the NACNC have failed to report upon the care of people with ME - one of the largest patient groups within their remit.** In relation to this item have tried to make contact with the Scottish Secretary of the Association of British Neurologists on a number of occasions but have been consistently rebuffed.
- **Given the points above and those made elsewhere in evidence to the Committee I contend that the petitioner's case for withdrawing GET for ME patients is now indisputable.** Even since my original letter the science demonstrating the organic nature of ME- and consequently the unsuitability of GET as an intervention - has advanced. If the argument for GET was ever tenable with weak data in the past it certainly is not now.
- **It is totally unacceptable for health practitioners in the NHS to deny the reality of ME and both the Secretary and CMO must act to expunge this harmful false belief.**

I look forward to your response and hope that we can move forward constructively on the issues raised.

Letter dated 28 February 2019

Thank you for the time and effort you put into your response to the Petitions Committee on the 24th of January. There were some very positive messages in your response some of which I have noted:

- *“I believe that ME is a disease that limits the quality of your life, I hear what you are saying to us, and your experience matters to me, as the Cabinet Secretary”*
- *“We need more research into the condition.”*
- *“The absence of data means that it is right that we should work on the basis of the lived experience of ME sufferers.”*
- *“Two of my fundamental principles on [realistic medicine] are shared decision making and a personalised approach to care”.*
- *“The World Health Organization, this Government and NHS Scotland accept that this condition exists...”*

However, last month I was approached by a lady in Fife who is severely ill with ME, exhibits worrying and debilitating neurological symptoms and is generally bedbound. Her GP persistently denies the reality of ME and refused to give her a letter excusing her from a court appointment on the grounds that she should “pull herself together”. I have also viewed the anonymous evidence that is shortly to be submitted to the Committee, which gives a grievous account of the treatment of her daughter. This continuing ill-treatment of ME patients continues on an almost daily basis in Scotland and **is totally inexcusable**. I am therefore grateful to Brian Whittle MSP for his persistent questioning on the subject of medical practitioners who refuse to accept the reality of ME.

I have recorded my response to specific issues raised during your response to the Committee and these are attached.

Neurological Conditions National Action Plan

The Cabinet Secretary has indicated that she expects this Plan to address at least some of the petitioner’s concerns: this is quite understandable given that ME is classified as neurological condition. The ME community has embraced the opportunity to influence healthcare planning in this area and the largest group of respondents to the research were ME patients. Nevertheless, the Scottish ME community have grave reservations about the commitment of the National Advisory Committee on Neurological Conditions (NACNC) to ME patients:

1. According to survey results reported in evidence PE1690_Y and elsewhere, over 80% of neurologists do not believe ME is a neurological illness;
2. Evidence of Scottish neurologists declining to see patients with ME has been presented to the Committee: see PE1690_X Appendix A;
3. The authors of the plan did not collect any data on the prevalence and disease burden of ME;
4. There are no existing neurologically-led services for patients with ME in Scotland.

The Government need to enquire urgently as to why the NACNC have failed to report upon the care of people with ME - one of the largest patient groups within their remit.

The Government urgently need to commission research to establish the prevalence and burden of ME.

Graded Exercise Therapy

Dr Calderwood is to be commended for stating that interventions should be agreed between the patient and the health professional and that refusal to accept an intervention should not prejudice ongoing care. Regrettably this does not address the situation concerning GET.

1. Suitability specifically for ME: Dr Calderwood expressed the belief that exercise therapies may be beneficial for some ME patients. It may be true that exercise is beneficial for some patients with *other conditions in which fatigue is a significant problem*, such as, for example, depression. However, the evidence that GET is harmful for patients *with ME* is now undeniable and has been presented in evidence to the Committee. The difficulty arises in separating patients with ME from those with other fatigue-presenting conditions but this can be circumvented by the use of up-to-date diagnostic criteria.
2. A patient can only grant consent for an intervention when properly informed of the risks. Given the woeful absence of ME awareness in the NHS it seems highly unlikely that patients with ME are receiving meaningful advice on the risks associated with GET: I have certainly never heard such advice.

Given the points above and those made elsewhere in evidence to the Committee I contend that the petitioner's case for withdrawing GET for ME patients is now indisputable.

Awareness

Ms Freeman states "*As there is a lack of sufficient evidence and research, it would not be especially helpful to get involved in an argument between clinicians who recognise ME and those who do not.*" (Column 37 of the meeting transcript). While I completely understand that a Government Secretary cannot dictate medical practice to a doctor, the experience of the Fife patient related in my letter (above) and many other experiences contained in the evidence to the Committee shows that it would actually be very helpful indeed to get involved in this argument – and to settle it, once and for all! While there is "a lack of sufficient evidence and research" about *treating* ME the evidence that ME *exists* and is a serious, debilitating condition is vast. It is essential to significantly raise awareness amongst health professionals and to forcefully challenge the "ME-deniers".

It is totally unacceptable for health practitioners in the NHS to deny the reality of ME and both the Secretary and CMO must act to expunge this harmful false belief.