

The Countess of Mar

Margaret Williams

22nd November 2008

There has been much comment on the letter recently sent out to numerous people by the Countess of Mar, one particular sentence of which was: *"I am greatly saddened that there is so much hostility to the NICE Guidelines and, specifically, to CBT/GET"*

I am in possession of the full letter sent out by Lady Mar, which also states: *"The whole point is that CBT/GET are not compulsory. At the moment there is no other universal treatment. Might I respectfully suggest that you read the NICE Quick Reference Guide carefully and, instead of vigorously opposing everything in them, you use its contents to empower people with ME to negotiate the best way forwards for them with their medical practitioners. This is my position. I hope it clarifies matters for you"*.

I have been contacted by many people – by email and by telephone -- inquiring if the letter really did originate from Lady Mar and if those can possibly be her views. People are shocked and distressed; they have compared her political lifetime's staunch support for the ME community, and especially her robust calls for biomedical research, with her current public support for the NICE Guideline on "CFS/ME" that recommends the national implementation of CBT/GET.

People felt there was now no hope if the Countess of Mar had "changed sides"; all felt betrayed and bewildered.

People were adamant that if Lady Mar remains as Patron of the various ME charities, then those people will cease to fund-raise for the charities. Someone who had just raised over £400 for an ME charity could not countenance sending the cheque. One person who contributes financially on a regular basis to an ME charity of which Lady Mar is Patron felt unable to continue doing so. The despair was tangible. People have commented that "she has shot herself in the foot" and are anguished in case her recent pronouncements might endanger the forthcoming Judicial Review of the NICE Guideline.

It is with profound sadness that, having spoken directly to Lady Mar about her letter, I can confirm that those are now her views and that she said she will not change her mind.

She does sincerely believe that the patient with ME should be in the driving seat and should be able to negotiate with the clinician about whether or not to undertake CBT/GET, as stipulated in the NICE Guideline. Perhaps because of her own experience (where she is treated with respect and generosity by consultants), she seems unaware that, for most non-private ME patients, such a partnership is unattainable in practice.

For the avoidance of doubt, the 25% ME Group for the Severely Disabled (of which Lady Mar is Patron) issued a Statement on 21st November 2008 confirming their position, namely that they maintain that the NICE Guideline on "CFS/ME" is not fit for purpose (a view known also to held by the ME Association).

The Statement notes that Lady Mar's faith in a "working partnership" between ME patients and clinicians is not borne out in practice. The Statement is clear: *"We support the Judicial Review into the NICE Guidelines on CFS/ME. For people with ME, these Guidelines are not 'a way forward'. All people with neurological ME can be assured that we do not support the view that CBT and/or GET is an appropriate treatment for anyone with ME"*.