

Promises, Promises ?

Margaret Williams 12th May 2007

Today is international ME/CFS Awareness Day. Today Gordon Brown MP, currently Chancellor of the Exchequer, launched his campaign to succeed Tony Blair as leader of the Labour Party and become Prime Minister of the United Kingdom. At 8.30am on the BBC Radio 4 "Today" programme, Brown began to speak of a "*new Government*" and announced his plans for the NHS, making it plain that there is to be more of a role for patients to play in improving healthcare. He spoke of patients having more control and more choice, and he said that what patients want is for their needs to be taken seriously. He promised to address the concerns of people about the NHS and said that one of those concerns is access to healthcare and he promised to concentrate on this. He said he would be going round the country "*listening to what patients tell me*" and that he would be "*working with patients*" and "*understanding peoples' concerns*".

This seems a remarkable reversal of his previous persona that was said to include insulting and contemptuous treatment of his fellow Cabinet Ministers and his reputation for being a control freak: on 21st March 2007 an article by former Cabinet Secretary Lord Andrew Turnbull in the Financial Times was uncompromising: "*There has been an absolute ruthlessness with which Gordon has played the denial of information as an instrument of power*".

As far as ME/CFS is concerned, the denial of information used as an instrument of power has been the hallmark of Blair's Government, of which Gordon Brown has been an influential member for the last ten years, so are his words today just empty promises? Will his plans include those with ME/CFS or will this particular patient community continue to be excluded from appropriate NHS investigation, care and support as at present?

It was in September 2001 under Mr Blair's Government that the UK Department of Health produced "The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century". This promised to utilise the knowledge and experience of patients themselves and promised that patients with chronic illnesses could become key decision-makers in the treatment process in partnership with healthcare providers. It stated: "*The era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it serves, one in which patients are empowered with information*". Its key recommendation was to "*promote awareness and create an expectation that patient expertise is a central component in the delivery of care to people with chronic disease*". The timetable for the full implementation was given as a six year period from 2001, with the programmes to be mainstreamed throughout the NHS by 2007.

This excellent strategy may apply to other disorders but it demonstrably does not apply to ME/CFS. As far as ME/CFS is concerned, it was nothing but an empty promise, as is

only too obvious from the subsequent actions of bodies such as the Medical Research Council (MRC), whose members and advisers have become ever more trenchant in ignoring not only patients' knowledge and expertise but also the scientific evidence upon which patients' knowledge is based.

The National Institute for Health and Clinical excellence (NICE) likewise has totally ignored the huge input from informed patients that was submitted during its so-called consultation process on "CFS/ME" and has continued to dismiss and exclude this solid source of knowledge and expertise.

Equally, in the publication of its policy document "The Occupational Aspects of the Management of Chronic Fatigue Syndrome: A National Guideline" in October 2006, NHS Plus has been even more forceful in totally excluding patients' expertise and experience to the extent that it undoubtedly puts an unknown number of patients at serious risk of harm. In an unprecedented action, a total of 18 UK ME/CFS charities have signed a joint statement expressing extreme concern at the bias expressed in the policy document and are calling for its withdrawal (see <http://tinyurl.com/3bh4af>).

Underpinning this resolute exclusion of ME/CFS patients' knowledge and expertise seems to be the direct intention of ignorant and ill-informed Ministers who favour the Blair Government policy about ME/CFS and who seem determined to accept the flawed advice of psychiatrists of the Wessely School that ME does not exist except as an aberrant belief and that CFS is a behavioural disorder.

All that this policy delivers for those with ME/CFS is a "management regime" that is handed out by about a dozen "specialist Centres" and which is designed to change the way patients think about their illness. There are no advanced investigations carried out at these Centres to confirm the many biomedical abnormalities known to exist in ME/CFS and offer the hope of addressing these abnormalities and no prospects of any cure, nor any intention to get to grips with the reality of the disorder, since most Centres are run entirely by mental health workers and occupational therapists.

This policy is promoted by Professor Lord Richard Layard (dubbed "the happiness tsar"), who stipulates that psychotherapy must be provided for all manner of chronic illness with the aim of removing people from receiving Incapacity Benefit. Last year, Layard published a report calling for a network of a further 250 centres to be staffed by 10,000 new therapists to deliver cognitive behavioural therapy, which in the case of ME/CFS includes graded exercise therapy (CBT/GET). However, Layard himself seems to be back-tracking, now conceding: "*I've never said CBT is a magic bullet*" (Happiness tsar warns of therapy funding shortage. Sophie Goodchild. Chief Reporter, The Independent, 6th May 2007).

CBT/GET is already known to be at best ineffective and at worst life-threatening in ME/CFS; it is widely acknowledged that the financial logistics of recruiting, training and supervising the extra 10,000 "therapists" seem currently insurmountable, so on what reputable evidence was £11.1 million provided to the Wessely School psychiatric lobby

to promote and provide this “rehabilitation” regime when it was already known not to work? The MRC has funded these psychiatrists to the tune of £2.6 million for the PACE and FINE trials which -- against universally accepted principles of research -- intentionally include a mixed patient population, whilst the remaining £8.5 million has gone into setting up the existing CBT/GET Centres to deliver this regime even before the outcome of the flawed trials is known.

It was thirteen years ago that the BMJ published an Editorial by DG Altman (The scandal of poor medical research. BMJ 1994;308:283-284). Altman did not beat about the bush:

“What should we think about researchers who use the wrong techniques, either wilfully or in ignorance, misinterpret their results, report their results selectively, cite the literature selectively, and draw unjustified conclusions? We should be appalled. Yet numerous studies of the medical literature have shown that all of the above are common. This is surely a scandal. Huge sums of money are spent annually on research that is seriously flawed through the use of inappropriate designs, unrepresentative samples and faulty interpretation. The length of a list of publications is a dubious indicator of ability to do good research; its relevance to the ability to be a good doctor is even more obscure. Carrying out an ill-designed study in ignorance of scientific principles and getting it published teaches several undesirable lessons. All too often the main reason for a piece of research seems to be to lengthen a researcher’s curriculum vitae. The poor quality of much medical research is widely acknowledged, yet disturbingly the leaders of the medical profession seem only minimally concerned. We need less research, better research, and research done for the right reasons”.

The ME/CFS community would argue convincingly that Altman was right, yet in awarding the Wessely School psychiatrists so much funding, the MRC has signally failed to take Altman’s warning on board. It is patients who are continuing to pay the price of the MRC’s arrogance in dismissing ME/CFS patients’ expertise.

At the recent highly successful Invest in ME international conference held in London on 1st-2nd May 2007, the issue of these psychotherapy Centres arose. In his usual robust manner, Professor Malcolm Hooper was critical of them (on the basis that they cannot possibly help those with complex neurological disease to recover and the only regime they offer -- CBT/GET -- could be potentially dangerous for some people with ME/CFS). He was dismayed to hear from one or two attendees that the Centres were better than nothing at all, a sentiment with which he disagrees. He was even more dismayed to hear the view from some attendees that the Centres should be supported by the ME/CFS community on the grounds that if patients do not attend these Centres, they will forfeit their entitlement to State and insurance benefits. When the Countess of Mar became aware of such a view, she was reported to have remarked that if this state of affairs is true, it is illegal.

Lady Mar was therefore asked directly if she had said this, and by email on 11th May 2007 she replied: *“During the Committee Stage of the Welfare Reform Bill – debates from Clause 9 onwards in the Lords, I managed to extract from the Minister statements to*

the effect that people with CFS/ME would not be forced to do CBT/GET in order to continue to get their benefits”.

That debate is recorded in Hansard (Lords) on 28th February 2007, column GC198:

Countess of Mar: "If a group of people refuses graded exercise and cognitive behaviour therapy, on the basis either that they are afraid or that they know it will not help them, will they be penalised?"

Lord McKenzie of Luton (Parliamentary Under-Secretary, Department for Work and Pensions; Labour Peer): "there is no requirement for individuals to carry out any specific type of activity or treatment. That cannot be sanctioned".

That seems clear enough but is it, too, just another empty promise?

It seems curious that neither the ME Association nor Action for ME – in whose respective charters is embedded the promise to act in the best interests of their members, many of whom are facing the very battle that the Minister has pronounced upon -- has seen fit to draw national attention to this momentous statement by the Minister. Had they done so, it would be difficult for the Minister's promise not to be honoured by Departments of State and by the medical insurance companies (as well as the company that administers NHS retirement pensions) without total loss of probity, as the whole world would have been made aware of it, but it seems to have been received with deafening silence.

Given that the MRC, NICE, NHS Plus and other Ministers have failed to keep the promise set out so clearly in the Expert Patient programme, it is imperative that neither Gordon Brown nor Lord McKenzie of Luton be allowed to escape personal accountability for their respective and very public promises.