

Leaving Patients in a NICE Pickle

Late in 2006, the National Institute for Clinical Excellence (NICE) published its “ME/CFS Guideline Draft For Consultation”, and raised a storm of protest from Registered Stakeholders, including ME Research UK. Its decisions often raise a rumpus, but there is something unusual — unique, in fact — about the current uproar. Today, almost certainly for the first time since it started work in April 1999, NICE is faced with a united body of patient-based opinion which does NOT want the guideline it has produced, certainly not in its current form, and if push comes to shove would rather have no guideline on ME/CFS than the one on offer.

In short, the draft is unfit for purpose — i.e., for informing the diagnosis and management of ME/CFS patients — primarily because it flags up as treatments for the illness psychosocial management and coping strategies that at best have an adjunctive role to play. Patient-based charities and self-help groups (and there are around 20,000 members of these in the UK alone) recognise this, and can foresee that the major recommendations of the guideline will not, unfortunately, solve the problem on the ground.

This is because the Institute has not got to grips with core issues surrounding ME/CFS. The first, and most central, is the problem of diagnosis: whichever definition is used, ME/CFS is widely recognised to be an impossibly wide diagnostic marquis and to contain different patient groups; the formation of clinical guidance inevitably raises the question of guidance for what and for whom. The second problem concerns the randomised controlled trial evidence upon which NICE puts a



premium, and the devaluation of evidence from scientific studies and surveys. In this illness, the evidence-base is skewed towards a small group of mildly positive trials on psychosocial strategies; thus, instead of finding the “best” evidence garnered from the work of a range of biomedical and biopsychosocial scientists working on a level playing field, what is found is quite modest evidence in a forgotten field put there by proponents of psychosocial strategies such as cognitive behavioural therapy (CBT). Multiple sclerosis with the formal evidence-base that currently exists for ME/CFS would be no less a physical illness, and the non-specific management and coping strategies would be no more specifically effective for the underlying disease, yet these adjunctive strategies have an unduly prominent role in the Institute’s draft guideline. The Table on the right illustrates this nicely. It shows that CBT is recommended as a specific treatment for psychological illnesses, but not for physical conditions. Except that is for ME/CFS.

The unfitness of this guideline draft is a terrible blow to people with ME/CFS, and we think that it should be withdrawn pending a complete overhaul.

ME Research UK’s full 9000-word critique of the draft NICE guideline can be read at our website. ●

TABLE

NICE Clinical Guidance recommendations on the use of CBT for 19 different clinical conditions

Is CBT postulated to be a specific treatment for the condition (Clinical Guideline number)?

Anxiety (22)	YES
Bipolar disorder (38)	YES
Depression (23)	YES
Eating disorders (9)	YES
Obsessive-compulsive disorder (31)	YES
Schizophrenia (1)	YES
Chronic pulmonary disease (12)	NO
Dementia (42)	NO
Dyspepsia (17)	NO
Type 1 diabetes (15)	NO
Hypertension (34)	NO
Lung cancer (24)	NO
Multiple sclerosis (8)	NO
The epilepsies (20)	NO
Parkinson’s disease (35)	NO
Familial breast cancer (41)	NO
Tuberculosis (33)	NO
Chronic heart failure (5)	NO
ME/CFS Draft Guideline 2006	YES