

PERMISSION TO REPOST

Campaigning for research into Myalgic Encephalomyelitis

RiME

NHS 'CFS/ME' Centres Condemned (RiME Newsletter Autumn 2005)

KENT

West Kent Chronic Fatigue Service (Leaflet):

This service aims to provide a locally based service for the management of CFS/ME. Similar to the treatment program at other specialist units, the emphasis is no rehabilitation, and is based in the principals of CBT.

How can CBT be helpful? CBT is a very practical approach which has proved helpful in the management of other physical conditions... and... also appears to be helpful in the treatment of CFS/ME... It aims to help you build on your own problem solving techniques, in order to discover the most useful ways of managing and overcoming your illness.

Assessment The aims of this session are to gather information about how your illness is affecting you... and how it began. It is also an opportunity to discuss the various treatment options... This appointment generally lasts.. 60-90 minutes, and can take place at Maidstone, Dartford or Tonbridge...

Waiting Times .. the waiting list is long, but an assessment appointment will be offered to you asap. You may find the following self help information useful in the meantime: 'Coping with Chronic Fatigue' by Trudie Chalder (Sheldon Press). Or if you have access to the internet, at: <http://www.kcl.ac.uk/cfs/>

Treatment If this form of treatment is the chosen option for you, it may be offered in either a group or individual format. Both group and individual programmes are aimed at helping you understand more about your illness and how you might manage it... Treatment is fairly structured and will generally include the following:

- monitoring activity levels
- establishing baselines
- setting goals for treatment
- moderating patterns of activity and rest
- sleep management
- relaxation training
- understanding and managing symptoms
- coping with flare-ups
- identifying and overcoming blocks to progress

What to expect .. treatment requires... commitment... tasks or 'homework' will be agreed and set at each session. Carrying out these tasks is a very important element of treatment, and good progress will not occur without it... Many people have found the CBT approach helpful and have continued to maintain their gains long after the sessions have finished. It is hoped that you will learn skills to sustain and build on improvements, and to cope with any setbacks that may occur.

Two people under the aegis of the 25% Group have been representing PWME in Kent. They have been trying to educate Kent Health officials about ME and are making the cardinal point that the condition described above is not ME, and that PWME do not want to be confused with people who have 'fatigue conditions'. The officials are looking at a system to implement their suggestions of 'monitoring' those who drop out, and trying to distinguish between them and the others.

Extracts from letters sent to West Kent Health Officials:

Sevenoaks:

.... ME and Chronic fatigue are being lumped together.... The CFS Service says it will treat 'CFS/ME' with CBT sessions.. by a psychologist.. This appears to have all the hallmarks of the 'Wessely School of Psychiatrists'. There would appear to be an erroneous assumption that PWME per se have low self-esteem and motivation, and negative thoughts, and therefore become inactive... this is not the case....

Bromley:

....You think that the Sussex/Kent CFS/ME Group represent 'the majority view'. I don't believe so. If 350 people in Kent belong to their Group, this would represent under 5% of PWME in Kent... People from Kent who have observed the leaders of the Sussex Group.. question... if they understand what it is like to have ME. Many are horrified by the fact the former will be on a Kent ME services Committee. Why were they appointed to this committee? And who exactly are they representing. I ask... (they) be replaced by people from Kent....

Meopham:

.... The question of nomenclature is all-important and I support, in this respect, the representations of the 25% Group. I don't believe the Kent Health Authority should proceed any further until this pivotal issue has been properly discussed and resolved. Can you tell me please why the 25% Group is only being heard at fringe meetings whilst the Sussex Group has been awarded a place on the Steering Committee? The Sussex representatives do not appear well-informed with their blind adherence to CBT modes of treatment, are not representative of ME patients in Kent...

Hampshire

Summary of Meeting of Hants Friends with ME in Southampton 6/7/2005

- 1. Michelle Selby, OT lead from Dorset Clinic + Clinical Co-ordinator of Southampton 'CFS/ME' Clinic, was late and ill-prepared.**
- 2. The office which will be used to treat 'CFS/ME' patients at Southampton is located in a mental health unit, and the treatment will be overseen by a psychiatrist - Prof. Peveler; his main interest is 'the application of behavioural science to the management of chronic health problems'.**
- 3. Information has already gone out to GPs which clearly states a psychological aetiology for PWME.**

4. MS said the terminology ME or CFS wasn't important. I disagree. The Fukuda Criteria will be used re. admittance. The latter does not adequately describe neurological ICD-ME and will mean that people with a range of illnesses/conditions will attend. I would have no problem with the Mental Health Team setting up a management service for people with unexplained fatigue - but

to call this an ME clinic is disingenuous to say the least.

5. When asked about referrals for other tests, MS made it clear this did not happen and there was no money available for this.

6. MS did not deny that OT training will be based on the Rationale for PACE Trials (MRC - PACE trial Identifier, early 2004). These are extracts from that document

Previously found predictors of a negative outcome with treatment include mood disorder, membership of a self-help group, being in receipt of a disability pension, focusing on physical symptoms, and pervasive inactivity.

There are three essential elements: (a) Assessment of illness beliefs and coping strategies, (b) Structuring of daily rest, sleep and activity, with a graduated return to normal activity, (c) Challenging of unhelpful beliefs about symptoms and activity... GET will be based on the illness model of both deconditioning and exercise avoidance, used in the previous trials.19,20,22 Therapy involves an assessment of physical capacity, negotiation of an individually designed home aerobic exercise programme with set target heart rates and times, and sessional feedback with mutual planning of the next fortnight's home exercise programme...

8. Hampshire Friends with ME had to declare an interest/support for the funding to be released. They have, unfortunately, obliged...

I have no faith in this program nor does anyone else I know in Hants. Exasperated GPs, who don't know what else to do with ME patients, will probably see the Hants Partnership Trust notepaper and GP protocol, and see this as an opportunity to shift responsibility for these people.

Sue Waddle 02392 252365 <http://www.investinme.org>

Kathleen McCall, leader of the Winchester and Eastleigh ME Group, says 'I endorse everything Sue has said. What makes me laugh is that to our face they call this the ME/CFS Clinic when in reality it's the Hants and IOW Chronic Fatigue Service.... We are meant to be reassured by the fact that the Southampton Clinic is modelled on the Wareham Clinic in Dorset. From correspondence I've received from PWME who've attended the Wareham Clinic, I'm not reassured at all, as Wareham seems to show a strong psychiatric bias of it's own. One ME patient at Wareham was told she was having treatment based on physical strategies for dealing with ME; they then wrote to her GP saying treatment was focused on 'identifying and challenging negative thought processes that could have hindered her recovery...' What PWME primarily want is proper research into their condition and, with this mind, we support RiME's efforts...'

Ed. These are not the only areas where PWME are opposing or challenging the NHS Centres. Jenny Griffin, for example, Chair of the Birmingham Solihull Group issued a statement 13/7/05:

"The members wish to express their deep concern that the patients' rep's... are clearly being excluded from any meaningful dialogue in the development of the new services for ME/CFS at the B'ham and WM CNCC and the S B'ham LMDT. Assurances were given that, although the B'ham + Solihull Mental Health trust was

chosen to 'site' the bid, the new ME/CFS services would operate independently from the psychiatric service. This is not the case....

Accordingly Solihull and S B'ham Support group have advised their patient rep's to disengage from any further participation... "

Further Concerns re.'CFS/ME' NHS Centres

(RiME Newsletter Spring 2006)

Shropshire

The following is taken from the Shrops Feb. Newsletter. In a statement 15/106 Dr S Myhill says:

... it is impossible for me to continue in a clinical role with Shropshire Enablement Team in their new venture offering services for patients with CFS. The fundamental problem is that I have not been given the clinical freedoms that I need in order to be able to treat patients effectively.

Not only do I not have any prescribing rights, but the clinical tests which I would like done have been refused funding. Furthermore, many of the very standard and very successful interventions that I routinely recommend for patients I am not allowed to recommend to GPs

So, for example, a very standard work up for any patient with CFS would include tests for mitochondrial function, hormone studies, together with recommendations for nutritional supplements (many of which are on NHS prescription), B12 and magnesium injections, desensitisation treatments and so on. But none of these am I allowed to implement, nor even recommend to GPs. This has made it extremely frustrating for both me and for patients, because I can tell them exactly the interventions they need to put in place, but I do not have the power to do them. Worse than that, when patients ask me how they can go about putting these things in place themselves, I am not even allowed to tell them that because this would result in a conflict between my NHS practice and my private practice...

Comments from colleagues in neighbouring West Midlands Groups (Shrops NL):

... having Sarah Myhill on board was one of the very few examples of imaginative thinking in these clinics. Unfortunately, within the NHS, practising defensive 'evidence-based' medicine seems to be the order of the day...

... the fact that her (Myhill's) patients were.. helped by her therapies.. was not going to sit well with the more conventional (and jaded) NHS 'bods' who boringly stick to their 'evidence based' therapies - quite where they get their 'evidence' from has always defeated me...

RiME ed. 'Evidenced-based therapies' = 'Wessely-type treatments' = more GE,CBT... ?

One of RiME's supporters from the W Midlands comments:

It is good to see there are still caring people in Britain willing to show back bone and take actions compatible with their conscience. Dr Myhill's decision to withdraw her involvement with SET, highlights exactly the concerns many ME sufferers have been expressing for a very long time, regarding the intended role of these alleged ME clinics. The necessary steps (both in the short and long term) are not being put in place to offer the vital investigations and treatment ME sufferers desperately require. Why then are our charities and local groups still willing to involve themselves with this farce? By doing so they are perpetuating the required impression that patient and public involvement is really significant in the setting up and implementation process, whereas the opposite is in fact the case. We live in an age in which politicians and their watchdogs cannot be relied upon to safeguard the interests of vulnerable people. We must therefore be prepared to fully

support individuals such as Dr Myhill who are clearly not willing to take the easy option, and give legitimacy to a political decision to reduce options available to ME/NHS patients under her care.

She has taken a brave stand and the very least the ME community should be prepared to do is stand with her!

London

A severely affected PWME says:

... the CNCC will be PW's clinic at Barts. ME is treated there as primarily as a psychological problem.. and patients offered GE programs... I don't understand why W was invited to address the x Group in North London. When asked its co-ordinator, apparently, said something about 'choice' - more GE, CBT... choice?? The co-ordinator also said something, apparently, about anything being better than nothing. I couldn't disagree more. Evidence eg articles from the Network MESH show the harm done to ME patients... overall, these clinics will work to the disadvantage of ME patients.

Manchester

One of our supporters writes

... everything about the Manchester CNCC suggests a stitch-up. The leading figure in the process is a psychiatrist Dr L. He appears to promote a psychosocial model of ME which fits in nicely with govt guidelines. Once again ME patients, those who suffer 24/7, are neglected and sidelined. Well done to the new Manchester Group for challenging what is happening here ...

Group Leaders and NHS 'CFS/ME' Clinics

Common concerns (not necessarily those of RiME):

- 1. That some do not seem to understand what ME is, and deem the same or similar treatment for people with a broad spectrum of illnesses 'CFS/ME' desirable.*
- 2. Related to 1. People complain that local Groups, like the National Charities, have become permeated by people who don't have ME, and don't understand what ME is. Some of the former might well benefit from the NHS clinics and canvass their implementation via the Group.*
- 3. That People with ME (esp. the severely affected) are not always consulted. Some Group leaders arrogantly assume that their members per se want the 'CFS/ME' services.*
- 4. That one or two connect the clinics to diagnosis. Diagnosis with what, exactly?*
- 5. That they never state what services, specifically, they are trying to get. They have no plan. So, instead of being the 'pied-pipers', they are shuffling along around the former's ankles.*
- 6. Political naivety: Some don't understand that those who run LHAs get to where they are because they do what Central Govt tells them to ie implement the recommendations of Govt Reports. If challenged, these people often say naively, 'working form the inside out' - (where did this get someone like Sarah Myhill?) or ' we hope to shape things as we go along' - they can't and don't > same old, same old...*

7. When it does go pear-shaped for PWME - some say, 'ah well, we tried... something is better than nothing'.

It's not - is the strong message we get. It's a lot worse than nothing (1) LHAs and the Govt can say what happened occurred with the involvement of ME parties (2) Treatment in some instances eg GE can prove harmful (3) imprecision re. admittance criteria to the clinics will > skewed results which might (a) delay or stop the Govt researching the physical causes of ME (b) lead to a situation where some ME patients' benefits are linked to their attendance of the mental rehab centres.

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