

YORK & DISTRICT

**ME**

SUPPORT GROUP

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**M.E. SUPPORT GROUP**

SUPPORTING PEOPLE WITH ME/CFS IN SELBY, YORK  
AND THE EAST SIDE OF NORTH YORKSHIRE

**HELPLINE**

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Monday - Thursday

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# NEWSLETTER FEBRUARY 2007

## NEW YEAR – NEW OPTIMISM?

I have had ME for a long time: too long. In the early days I tried various, often dubious, and sometime plain wacky, treatments that were about. Not too surprisingly they had little effect and, to be honest, when that month's miracle (and usually expensive) cure did not work I was pretty devastated. Every method had someone saying how much it had improved them but this only ever appeared to be a marginal improvement and then for a select few, for a short time. In the end I gave up trying and used a careful regime of rest and activity (a sort of pacing) that worked reasonably well to control things.

I now think things are changing ... there appears to be a number of, well ok, lets be honest, dubious sounding and expensive treatments but they do appear to have some very promising results. A common feature is a problem with various hormonal systems, such as the thyroid, adrenal, immune and others within the body, often controlled by a part of the brain called the hypothalamus. At this point I must apologise to all those who I am misrepresenting because this is very much my own warped and ignorant interpretation.

There appear to be two major approaches to this problem: taking hormones directly (as advocated by Doctors Peatfield and Myhill) and a talking approach (such as Reverse Therapy, Mickel and Lightning Therapies). I have had more direct contact with the latter, which appeal as they do not involve taking a cocktail of rather potent drugs.

So how can talking stop, cure or help ME? None of them consider ME to be psychological, all in the mind or trivial. They take slightly different approaches but there appears to be a common thread that they allow the body to get out of a state that is either caused by or causes ME. This involves a lot of work on your part; one has to be committed and is not for the faint-hearted. It is difficult to measure ME improvement so things are very controversial, but some have claimed very high success rates. They are not perfect but I think they are worth investigating and may well lead onto an even more successful method. From my own experiences with Reverse Therapy there is a unique feeling when things click and come right which I have not had in the years of ME.

Is it time to be more optimistic for future treatments? I think it could be.

*Richard.*

*We would be very interested in any response from readers to Richard's article.*

## **Media Watch**

In the past this column has expressed some cynicism about the Daily Mail's coverage of ME, and, in particular, its propensity to push various 'wonder cures.' The article in the January 9<sup>th</sup> 2007 edition could be dismissed as another in the Mail's "Is this the cure for ME? Series". In fact the article, which appeared under the heading "Could ME be caused by too much adrenaline?" was an interesting case study on 17 year old Leonie Gough, who believes she has been cured by the 'Lightning Process' (see Autumn 2006 Newsletter where we referred to it as 'Lightning Therapy').

A year ago Leonie was practically bed-ridden with ME. Now she has returned to full time education thanks to "a simple mind programme called the Lightning Process". Central to the Lightning Process is the notion that adrenaline plays a key role in ME, and that sufferers are caught in an 'adrenaline loop' of fatigue – anxiety – adrenaline – fatigue.

However the Mail, also, quotes Dr Neil Abbott of ME Research UK, who points out that there is, thus far, no scientific evidence of an adrenaline rise in ME. "The only thing that will create general acceptance of the principles and treatment techniques applied by the Lightning Process will be large scale tests" he cautions.

*Brian*

## **A Note from the Editor**

Although we have had a few welcome articles from readers recently, this newsletter still relies too much on the contributions of a handful of individuals. It would, I'm sure, be better if it reflected, to a greater extent, the views, anxieties, and opinions of the wider membership of the ME Support Group. Your contributions and feedback are very much needed. Also, if you see or hear anything interesting in the media about ME, do let us know. Don't assume we've already seen it. Contacting the ME Group – By phone: call Sandra – 01347 810841; E-mail: newsletter @ yorkmesupport.org.uk.

Newsletter Editor: Brian Elmer, 101 Bellhouse Way, YORK, YO24 3LW.

## **Disabled Persons Railcard**

Eligibility criteria for this scheme have been broadened to include anyone receiving long term Incapacity Benefit, or DLA at any level. The railcard is £18 for one year and £48 for 3 years and users can get a third off most train tickets, plus certain hotel discounts. Do not apply at a station, but phone 0191 218 8103 for application form/booklet.

## **Fundraising Events**

The ME Support Group will be holding a fund raising collection at Dean's Garden Centre, Stockton on Forest on Saturday, 7<sup>th</sup> July. More on this in the next newsletter.

## **Candida and M.E.**

I have heard many times from people suffering the symptoms of ME/CFS that they have tried the Candida diet and it doesn't really work for them. What most of them fail to realise is that despite what some nutritionists say, this can be a long term project also, a very strict regime, and only those determined to be well will stick to the course and succeed.

Although Candida may not be the main cause of ME/CFS, it is more than likely a great contributor to the illness. Along with other conditions such as allergies, hypothyroidism, toxic liver, low adrenal function, it can put an immense pressure on the immune system. By killing off the Candida with diet and anti-fungals and building the body's own defences with supplements and pro biotics, it gives the immune system such a boost that it can start to deal with the other things going on.

I have experienced this for myself. I have been following a course of action suggested by Erica White, a nutritionist now, but who suffered for the first 52 years of her life with all the symptoms of ME and more. She eventually got herself well and went on at the age of 55 to carve out a career for herself as a nutritionist in order to help others with the same problems.

I strongly recommend reading her books – Beat Fatigue Handbook and Beat Candida Cookbook. She recently had published the results of her clinical trials of the Candida regime on sufferers of ME/CFS in a leading medical journal, The Journal of Orthomolecular Medicine. It will be interesting to see the outcome of that.

Although Erica retired this year at the age of 71, her company Nutritionhelp continues to help hundreds of sufferers. She does still however, lecture to groups on the subject throughout the country, when requested.

Anyone wishing to know more can log on to her website at [www.nutritionhelp.com](http://www.nutritionhelp.com).

Good Health to you.

*Susan Bunt.*

*Editors note:*

*We hope to get Erica White to talk to the group sometime in 2007.*

### **ME Group Meetings**

The experiment of moving on meetings to afternoons at the Holmefield Centre, Peel Close, Heslington has led to an increase in attendance, so we are continuing with the arrangement. The next meetings are on:

Wednesday, 7<sup>th</sup> February 2 pm – 3.30 pm

Wednesday, 7 March 2 pm – 4 pm. The meeting will be addressed by Azizah Clayton, York based nutritionist.

If there are any topics you would like to raise with her, could you let us know at the February 7<sup>th</sup> meeting.

**There will be no April meeting, due to Easter holidays.**

THE DEADLINE FOR CONTRIBUTIONS TO OUR NEXT NEWSLETTER IS  
16 March 2007

Disclaimer: The inclusion of information of any kind in this document does not imply a recommendation of guarantee of accuracy, nor any views or comments

**F R I E N D S H I P      N E T W O R K**



Members of the network should have an updated contact list with this newsletter. If you don't then do let me know. The network is going well and we have many members across our area.

If you would like to join please send me a stamped addressed envelope  
**For details of the Group's Friendship Network contact  
Sandra Tomlinson on 01347 810841**

***The group needs someone to take on the running of the Friendship Network.***

***If interested please contact Sandra on the above number.***

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**CAN WE SEND YOUR NEWSLETTER BY E-MAIL?**

If so, please let me have your e-mail address  
Sending the Newsletter in this way will cost us nothing, helping the group enormously.

The Scarborough ME Group

The group meets on the 3rd Monday of the month at members' homes at 2 pm. For details contact Lynda Moore-house [lyndamoorehouse@hotmail.co.uk](mailto:lyndamoorehouse@hotmail.co.uk)  
For those of you on-line

A great website for saving money is [moneysavingexpert.com](http://moneysavingexpert.com), run by Radio 2's money saving advisor Martin Lewis. It's a regularly updated and advises on sites covering everything from cheap travel, insurance and banking, downloading free antivirus software and getting cheap phone calls.

For example, at the moment you can get **free UK landline phone calls—you just pay a connection charge of 4p per call**. I've tried this over the past 3 months and have spent only £1.50—saving well over £10 a month! To do this set up an account at [www.1899.com](http://www.1899.com) and then put '1899' before ordinary any UK numbers that you dial. Other providers are cheaper for phoning abroad and mobiles and it's not so cheap for 0845 type numbers. It is also slightly different from none-BT phone line renters.

## NHS Services

### Primary Care Trust (PCT) Changes & Financial Problems

The PCTs are an important part of the local nhs, taking the lead in shaping, planning commissioning and in some areas, providing a range of health services. They are required by the Department of Health to implement the modernisation agenda and initiatives such as waiting time targets as set out by the Government. They have recently been merged as part of the drive to create a 'patient led nhs'. In October 4 PCTs in North Yorkshire were merged to form the York & North Yorkshire PCT.

The new Trust, based in Harrogate, is geographically the largest in England; covers the third largest population – 765,000 and has some of the geographically most remote areas. It has a budget of more than £850 million (2006/7) and employs around 5000 staff. It works with local groups, GPs and has offices across the county to maintain responsiveness to local needs. Provision of advice and information on local NHS services continues via the Patient Advice and Liaison Services (PALS), (details in phone book.)

Unfortunately though changes are regarded as primarily management and administrative the local PCT debts have also been combined. This has created a PCT that is one of the most in debt in the country. It is predicted it will be ending the financial year in March in the red to the tune £24.5 million, despite substantial savings measures (York Evening Press 20<sup>th</sup> December). There is concern about the impact as the Trust attempts to claw back money by the end of the financial year.

On 4<sup>th</sup> November the Press reported plans to save money including: £5million from managing medicines better, which includes prescribing cheaper, non brand-name drugs; £25.1million in the amount of services it commissions from other health providers like hospitals; £10.1million in internal cost and £2.2million in management costs.

In the Press of 20<sup>th</sup> December Dr David Hartley, chairman of York Health Group, said: "My worry about patient care is that patients are going to see a reduction in the spread of care that they have been accustomed to in this area. They're going to be made to wait longer for out-patients, longer for in-patient admissions, they're going to be made to wait up to national limits."

A PCT spokesman said the trust had been working to verify the current financial situation since it was established on October 1. "In order to restore the North Yorkshire health economy to financial balance we must develop a robust plan that not only provides the local population with a fully integrated range of safe, accessible and high-quality services that provide value for money but is also linked to service modernisation being reactive to the changing needs of our population "The ongoing challenge for all of those involved in local healthcare provision is that within the resources we are allocated and as part of developing this plan we need to actively engage our local population and key stakeholders such as the GP community and local hospitals trusts so they play an active part in the decisions we take."

**THIS DOCUMENT IS AVAILABLE IN LARGE PRINT**

**NICE guidelines for CFS/M.E.**

In 2004 the government announced the plan to develop Clinical guidelines for the diagnosis and treatment of CFS/M.E. by the National Institution of Clinical Excellence (NICE) as part of its strategy for improving care for people with CFS/M.E. It was hoped that these guidelines would provide advice to people with M.E., their carers and health professionals on best practice NHS treatment. These guidelines are due to come out next year and are now available in draft form. The eight national charities have united to express concern about serious flaws and have called for a major rewrite. They fear the guidelines will hinder rather than help doctors treat those with CFS/M.E. Their statement is as follows:

**STATEMENT BY ME CHARITIES ON DRAFT NICE GUIDELINE FOR THE TREATMENT OF ME/CFS – December 2006**

We support the view that doctors and other health professionals require comprehensive balanced guidance on the clinical assessment, diagnosis and management of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME / CFS). We fully support the principles in the guideline governing the way in which patients must be actively involved in decisions about the management at all stages of their illness and that the principles of informed consent are paramount.

However, the proposed guideline has a number of serious flaws:-

The guideline fails to reflect the fact that ME/CFS is a physical illness classified by the World Health Organisation and the Department of Health as a neurological condition. The guideline recommends the blanket use of cognitive behaviour therapy (CBT) and graded exercise therapy (GET) as the treatments of first choice for ME/CFS when :- Neither treatment can be justified for all patients on the research evidence.

Neither treatment is acceptable to the majority of patients.

There is patient evidence that GET has the potential to cause damage to patients.

There is patient evidence that CBT is not an effective treatment and can have adverse effects.

The guideline has so widened the definition of ME/CFS as to include almost everyone with chronic unexplained fatigue

We believe that the proposed guideline should :-

Take more account of direct patient experience of the illness. The failure to do so is particularly ironic when Government's guiding principle for the NHS is that it must be patient led.

Reflect the point that 25% of people with ME/CFS-some 60,000 people – are bed or house bound.

Acknowledge that 25,000 children have ME/CFS and that it is the biggest cause of long term sickness, and absence from school.

Offer a portfolio of treatments and symptom control options according to need.

Take more account of, and acknowledge, the wealth of biomedical evidence.

ME/CFS is an illness that currently has no cure and no simple diagnostic test. Research is desperately needed into the underlying physical cause because without this knowledge there will be no effective treatment.

We – an alliance of national ME Charities – require that NICE instigate a major rewrite of the guideline. There must be much greater involvement of health professionals who accept the physical nature of the illness and representatives of the patient community. The patients have this illness, their carers and physicians see its debilitating effects, and yet their evidence has been sidelined. This is contrary to those very principles which NICE agreed to follow.

The M.E. Association-Action For M.E. – The 25% M.E. Group – The Young M.E. Sufferers Trust – CHROME – The National M.E. Centre – BRAME – The Association of Young People with M.E.

.....An additional statement has been made by the Tymes Trust, BRAME (Blue Ribbon Awareness of ME) and The 25% ME Group is available at [www.25megroup.org](http://www.25megroup.org)

(The impact of the changes on local people with ME/CFS, especially at the PCT is as yet unclear. We have had a good relationship with both the Leeds Clinic and the PCT over several years, and are working to maintaining those and promote positive changes. We hope to be able to continue to move service development forward on an informal basis with Leeds. I am very busy at the moment...If you have some spare time and relevant experience (e.g. in composing letters) to help, then do give me a call on 01904 655911. Jenny)