

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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NEWSLETTER SUMMER 2007

Welcome to the Summer Newsletter of the York and District ME Support Group.

Annual General Meeting

The group held its AGM on July 3rd. The committee elected consisted of

Sandra Tomlinson (Chairman), Jenny Gilmore (Treasurer), Brian Elmer (Newsletter) and Linda Dales. Richard Canham has decided not to continue on the committee but fortunately is still involved in the group, and will continue to run our web-site. The York ME Group would like to thank Richard for his service on the committee, and for all work he has put in.

In Sandra's report to the AGM she noted the good news that several members have regained their health.

Also, Jenny our treasurer has obtained grants from the Collinson and Purey Cust Trusts, which enables us to send a free newsletter to our 229 members. These grants also cover the costs of the friendship Network, the membership of which stands at 43.

During the past year we have changed our monthly meetings to the afternoon and more people have been able to attend. The feedback received indicates that people have found these meetings helpful.

ME Group Meetings all on the first Wednesday of the month:-

Wednesday 5 September	2 - 3.30 pm	Talk on Reverse Therapy by Lyn White
Wednesday 3 October	2 - 3.30 pm	Talk on Lyme Disease by Joan Crawford
Wednesday 7 November	2 - 3.30 pm	Talk on the Lightning Process by Jenny Gilmore

Check website for further meeting details or phone 01347 810841
All meeting are held at the Holmefield Centre, Peel Close, Heslington.

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.

We are frequently in this newsletter, urging our readers to contribute and respond to articles that appear. We are grateful to Stacey Lord for the following contribution.

There have been a number of articles recently on Lightning Process/Reverse/Mickel Therapies etc. claiming they can cure M.E./CFS and the therapists treat it as a physical problem. How many other purely physical problems have you heard of being cured by talking? M.S.? Cancer? HIV/AIDS? Diabetes? None! These therapies don't work for everyone who tries them and I believe just as some people with M.E./CFS get misdiagnosed with a psychological/psychosomatic problem it can work the other way too i.e. a psychological/psychosomatic problem is diagnosed as M.E./CFS and its these people who are being helped. Don't get me wrong, I believe a psychological problem can be just as debilitating as M.E./CFS and is therefore no lesser of a problem, it just needs treating in a different way.

Obviously mind and body can't be separated, they were designed to work together or we wouldn't function, but unless you see a complementary therapist for something like homeopathy, treatments are primarily aimed at treating either a physical or psychological problem. I would also agree it's important to deal with secondary or separate psychological/emotional problems to take the added stress off the body. But recognise these for what they are M.E./CFS is not caused by stress – isn't that what we've been campaigning for all these years, to recognise M.E./CFS as a physical condition?

In another article in May 2007 newsletter "So what is CBT anyway?" it was said that CBT was ...the first choice treatment for anxiety, depression, eating disorders, obsessive compulsive disorder, post traumatic stress disorder and even schizophrenia, all of which, of course, really are psychological problems...' and the point was argued it was therefore unsuitable for treating M.E./CFS. However, a website I checked for information on Lightning process used these exact same psychological conditions (except schizophrenia) and M.E./CFS stating it could cure them! If we're so sure CBT can't cure a physical problem why are some people saying Lightning Process and others can? They are based on the same principles i.e. altering negative thought processes and changing behaviour patterns.

Patients are hand picked by therapists after they have completed questionnaires and ticked all the right boxes, which probably explains the apparent high success rate. The cruel twist comes if the patient fails to respond to treatment as they are blamed for the 'failure'. Who would choose to spend hundreds of pounds on a treatment they didn't want to benefit from?

Personally, as much as I want to get better, I have no desire what so ever to try any of these therapies. Instead I'll rely on listening to my own body and advice from my G.P. to know what's right for me and nobody should be made to feel guilty for not wanting to try these approaches, we have enough to deal with!

A couple of side issues, Sandra said in her article 'A perspective on M.E./CFS as chronic stress' 'It is important when assessing any treatment to remember that M.E./CFS is NOT a true diagnosis but a group of symptoms, which conventional medicine does not understand, thus it's called a 'syndrome'.

Firstly the word 'syndrome' means a collection of symptoms NOT that conventional medicine doesn't understand it. Think of Downs syndrome etc. Also M.E./CFS IS a true diagnosis otherwise why are there guidelines on diagnostic criteria, some of which are quite detailed?

Also Sandra claims M.E./CFS is caused by a dysfunctional HPA axis. If that's the case shouldn't M.E./CFS be classed as an endocrine problem rather than neurological? Equally treatment using Thyroxin isn't for everyone. I have personally been warned against this as I have an unexplained fast heartbeat (not caused by raised adrenaline as I had a 24 hour urine test done on the NHS by my G.P. to check for this) and it could prove to be dangerous to follow this path.

Editorial Comment

Stacey raises important issues and contradictions from the world of CFS/ME related to cause and effective treatment. The Group seeks to make information available on a wide range of ME related topics, and has covered many different approaches over the years for our members to investigate if they wish. This includes mickel/reverse/lightning process, adrenal and thyroid approaches as well as mainstream approaches recommended by the nhs such as pacing, which have benefited our members. Some complementary approaches are expensive and different things suit different people. The Group does not recommend a particular approach to treatment.

We also received this contribution from Lyn White, Reverse Therapist.

I've just been reading your May newsletter online, and you asked for comments on ME and HPA axis- so here's mine!

To the person who said "how can talking help a physical problem?" I would say emotions are very physical (mediated by chemicals including neuropeptides) and arise in the body. Emotions are sent to guide, warn and protect us – if we repeatedly allow our head/mind to overrule, ignore or distort the action our body needs to satisfy the emotion, then that is what sets off the alarm response in the hypothalamus. The hypothalamus then sets off the cascade of responses through the pituitary and sympathetic nervous system which lead to the many and varied distressing symptoms experienced by people with ME. RT is a supportive coaching process which enables people to become aware of emotions as they arise and then to speak and act on them so the hypothalamus no longer needs to send symptoms.

ME and Coeliac Disease

I was diagnosed with ME in the 1990's and forced to take early retirement. Earlier this year, having had some improvement in symptoms, I started to do a little part time work. On the advice of the chair of this group, Sandra Tomlinson, I decided to have some private medical tests done. My thinking was that this would be a good investment, as I did not want to increase my hours of work, and then find that I could not manage.

My tests were saliva sample tests by mail (via the Red Apple Clinic, of Newport, Wales). My expectation was that possibly a Thyroid problem would be revealed, but fortunately I opted for a range of tests. I say fortunately because to my surprise the clinic informed me that I had "moderate to severe gluten intolerance" a condition known as coeliac disease.

The reason that I was surprised by this is that I had absolutely no digestive type symptoms - such as bloating, stomach pain, nausea or diarrhoea, which I would have thought to be typical of a gluten intolerance. However I have had the diagnosis of coeliac disease confirmed by a blood test at my GP, and, more recently, by a gastroscopy at the York District Hospital. It appears that coeliac disease can come in different forms: one version presenting chronic gut symptoms, and a second 'atypical' form presenting few or no such symptoms. In this second form the main presenting symptom is generally chronic fatigue.

Having coeliac disease is certainly a nuisance. It means that I am unable to eat gluten, a protein found in wheat, rye, barley and oats. Any gluten I do eat damages my small intestine, and means that I cannot digest and absorb nutrients from food properly – hence the fatigue problem. Many people with coeliac disease are anaemic as a consequence (as I was). A large range of foods are off limits including proper bread and proper beer (the ersatz gluten free varieties of each are frankly unpalatable).

Nevertheless, I regard this diagnosis as hopeful. It means there is something I can do about my fatigue problem. The downside is that it can take the intestines up to a year to recover, and I have only just been diagnosed. I have noticed no real improvement yet.

The question that arises now is: have I really had 'ME' or was it undiagnosed coeliac disease? The consultant at the District Hospital believes, having looked at my medical history, that I have been coeliac for several years. My feeling, is that when I became ill originally it was definitely not coeliac disease, but perhaps coeliac disease has been perpetuating my problem over recent years. I really don't know, but at the very least coeliac disease is a large part of my fatigue problem.

Being diagnosed as having 'ME' was for most of us a relief, having suffered with alarming and debilitating symptoms. At least we know it is not something life threatening. It seems to me, though, that it is a double edged sword. Once we are labelled as having 'ME' then all further investigation tends to cease. We are told to go home and relax or pace ourselves. I am not saying there is not a disease called 'ME', but that the label can cover a range of fatigue states which may have other causes. It has been estimated that as many as 1 in 100 people in the UK could have coeliac disease. How many of them have been told they have 'ME'?

Brian

Media Watch

On 19th April the Press ran the story of Christine Wrightson of Huntington, who became bed-ridden with a chronic fatigue problem. In April 2006 she had a test done on her adrenal glands at York Hospital. The test results showed that nothing was wrong. Nevertheless Christine continued to deteriorate and some months later tried a different route to get her condition diagnosed: private saliva tests done over a 24 hour period. This tested her continuous levels over this period and revealed that she was suffering "adrenal exhaustion". Now Christine is on medication which she pays for herself but which she feels is finally improving her condition.

Christine feels strongly that her original tests should have been done over 24 hours rather than as a one off. In this opinion she is supported by Professor Hooper professor of medicinal chemistry at Sunderland who has stated " the tests can not be done as a single measurement they have got to be done over 24hours"

The Press also printed a letter in response from Sandra Tomlinson chairman of this group who pointed out that some ME sufferers had found a reason for their fatigue via saliva hormone testing offered by private laboratories, and that such laboratories are accredited as are NHS laboratories.

THE DEADLINE FOR CONTRIBUTIONS TO OUR NEXT NEWSLETTER IS 19 NOVEMBER 2007

Please send articles for inclusion to newsletter@yorkmesupport.org.uk

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 necessarily those of the group.

Northhallerton ME Group

The Northhallerton and District Group meets on the 1st Monday of each month at the Cottage Meeting Room, Northhallerton Methodist Church, Northhallerton from 1.30 – 3.30pm. The group is always pleased to see new members from Northhallerton and the surrounding area. For further information contact Gillian on 01609 779452 (between 1.30 and 6pm Monday to Friday).

Scarborough ME Group

The Scarborough Group is still meeting at various members homes if interested please contact Lynda Moorehouse via lyndamoore@househotmail.co.uk. The Group hopes to have a presentation on the Lighting Process at sometime in the Autumn.

On Line Petition

The petition below will be presented to the Prime Minister. You can sign up on http://petitions.pm.gov.uk/ME-is_real/.

“We the undersigned petition the Prime Minister to get the Health Service and medical profession to accept the World Health Organisation classification of ME/CFS as an organic neurological disorder and not as a psychosocial syndrome”

The deadline to sign up by ; 22nd January 2008

Benefits Site

www.benefitsandwork.co.uk

This alternative benefits website is run by former Welfare Rights Worker Steve Donnison. Much of the information is free although some require a subscription of £16.50.

Nice Guidelines

NICE is due to produce guidance for NHS staff managing ME patients on 22 August 2007. Earlier drafts have been severely criticised by all patient organisations who regard this guidance as not fit for purpose and have felt that views from patient groups and people with the condition have not been properly taken into consideration. Issues include over reliance on CBT and graded exercise, poor management advice during the early stage of the illness and symptom management advice in later stages of the condition, and the way it deals with the severely affected.

On Saturday 15 September on The ME Association has organised a public meeting in Peterborough at which Professor Richard Baker (Chair of the development group) and other people from NICE will present the new guideline and describe how it will be implemented within the NHS.

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

New Department Works Pension Medical Guidance for Disability Living Allowance

This advice for assessing doctors and benefits agency staff came into effect on 20 July and has been rejected by patient organisations. Wording means that people with moderate ME/CFS will continue to experience difficulty in obtaining either care or mobility components of DLA. While implying that people with severe CFS/ME may be eligible for either or both components of DLA, the still very inadequate description may mean that a significant proportion of people with severe ME/CFS may not achieve the level of benefit to which they are entitled. There is no mention of the fact that ME (and CFS by link) is classified as a neurological disorder by the WHO in ICD10. Neither is there any mention of the more severe neurological symptoms – eg blackouts, swallowing disturbances – that were carefully noted in section 4.2.1.2 of the Chief Medical Officer's report.

Both these issues have been raised at the Houses of Parliament All Party Parliamentary Group on CFS/ME. (See ME Association website for minutes/Action for ME website or websites of other national ME organisations). Please consider contacting your MP on either or both of these important issues.

“We hope that shortly that our Group Letter to local Members Of Parliament will appear on our website” Jenny

New Under Secretary Of State

Ann Keen MP, the new parliamentary Under Secretary of state at the Department of Health, has been given the responsibility of overseeing the Department's work on ME.

Completing Benefit Forms

It is always helpful to get advice when completing benefits forms as the way you complete them can affect the level of benefit that you receive. Action for ME and the CAB Have good information available and local disability/carers organisations (and some local councils) often have benefits advisors.

Closure of DIAC

The Disability Information And Advice Centre who have provided benefits advice and other help to many people with ME/CFS in and around York is to close in September. Their funding from the Primary Care Trust has been withdrawn.

Free Disability Directory Enquiries

BT run a free Directory Enquiries service for anyone who cannot hold, handle or read a phonebook. You don't need to be billed by BT to take advantage of the facility, but you will need to inform your call time provider to ensure that you are not charged for the call. All you need to do is fill out an application form and provide evidence of your disability. To register please telephone 0800 587 0195.

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