

YORK & DISTRICT ME
SUPPORT GROUP
 SUPPORTING PEOPLE WITH ME/CFS IN
 SELBY AND YORK AND THE
 EAST SIDE OF NORTH YORKSHIRE

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NEWSLETTER DECEMBER
2005

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*Welcome to the Newsletter, and a Happy Christmas
 and a Healthier New Year to all our readers*

EARLY DAY MOTION

Early Day Motion 250, the House of Commons motion referred to in the last Newsletter, calling for more Government funding for ME research has now been signed by about 200 Members of Parliament.



HOME STUDY

John Dean, tutor with the Association of British Correspondence Courses (ABCC) contacted us about home study English Literature and Languages course he tutors through Craven College, Skipton, enabling people in the Moors, Dales and Vales in North Yorkshire to study GCSE or A Level at home with a home study pack. Support includes flexitutorials with other students at coffee/tea shops in Malton, Pickering, Thirsk, York and Kirkbymoorside. For further information about the courses ring the home study co-ordinator at Craven College on 01756 708003. For further information about learning at home with ABCC Tel 020 8544 9449 or visit the website on www.homestudy.org.uk

PROPOSED NHS REORGANISATION

Brian and Sarah attended a meeting at the Priory Street Centre, York, in September, concerning NHS reorganisation proposals. It seems that more power is to be given to GP's, or rather groups of GP practices, so that they can 'commission' the NHS services they require. This seems to be a return to GP fund holding and will mean, ultimately, a reduced role for Primary Care Trusts (PCT). Consequently, the number of PCT's will be reduced with the likely outcome of one PCT for the whole of North Yorkshire.

PUB SOCIALS

The Group meets at 7.30pm on the first Wednesday of each month at The Black Swan, Peasholme Green, York

There will be no January meeting

Future Topics:

February 1, 2006	Vegepa
March 1, 2006	Thyroid Update
April 5, 2006	Candida

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



MEDIA WATCH

In the last Newsletter we reviewed Dr Basant Puri's book on Chronic Fatigue Syndrome and the possible advantages of treating it with 'vegepa' – a fish oil/evening primrose oil combination. Shortly after this, Dr Puri appeared on BBC television's 'Horizon' which focussed on the advantages of taking this kind of supplement. Although ME wasn't specifically mentioned, Dr Puri outlined the very positive results he has also had in treating depressed

patients with 'vegepa.'

Radio 4's 'Case Notes' programme covered chronic fatigue states in general, and the varying reasons for them. There was a discussion of ME featuring Professor Leslie Findlay of the National ME Centre, Essex.

The latest research would indicate, he said, an average duration of 3-5 years, but that 40% of sufferers would never return to their previous level of functioning. As far as the treatment is concerned, Professor Findlay still feels that the underlying condition is hard to treat, but that a great deal can be done to ease the symptoms. He seemed quite well disposed toward the use of cognitive behaviour therapy, but dismissive of crude graded exercise programmes, which he felt could be detrimental.

In the April 2005 Newsletter we summarised the then Work and Pensions Secretary, Alan Johnson's, plan for Incapacity Benefit. It now seems that this is far from the last word on the matter. Alan Johnson's successor, David Blunkett was interviewed on Radio 4's 'You and Yours' programme, in October and announced he would be "building on" Johnson's proposals in a new Green Paper this autumn. He announced an intention of getting 1m Incapacity Benefit claimants back to work.

Of course, David Blunkett is himself an ex Secretary of State, and the position of the proposed Green Paper is not known. It may be that even more concerning proposals are in the pipeline. The 'Guardian' of November 2 2005 reported that "The Prime Minister is said to be pushing for a much more macho approach. He is reputed to want stricter time limits on the benefit, and at a reduced level." Some journalists have described new Secretary of State John Hutton as a 'yes man' appointed to do the Prime Minister's bidding. Against this is the new found propensity for rebellion amongst Labour Back benchers, which could scupper more extreme proposals from No 10. What all this means for ME sufferers on Incapacity Benefit is far from clear.

BRIAN

PS: We hope to cover the more positive aspects of the Government proposals in the next Newsletter, ie, what positive help is available to those now well enough to consider a possible return to work.



ME AND MITOCHONDRIAL DYSFUNCTION

In an article that generated a lot of interest ME specialist GP Dr Sarah Myhill describes how poor function of our cell's batteries, the Mitochondria, can reduce the energy supply in our cells. She shows how many symptoms of ME/CFS can be explained by resulting inadequacies in heart function and blood supply and suggests treatment for Mitochondria using supplements such as L-carnitine, Co-enzyme Q10 and D-Ribose, where deficient. The full article is at www.drmyhill.co.uk. Thank you to Bob for highlighting this.

**THIS DOCUMENT IS AVAILABLE IN LARGE
PRINT**

A NEW APPROACH TO TREATING CFS/ME AND FIBROMYALGIA

Action for ME's August magazine had an article on *Reverse Therapy and Mickel Therapy*, two still controversial therapies based on the assumption that symptoms are caused by a dysfunctional hypothalamus. The following is a member's experience of the Mickel Approach.

I was a healthy, fit, and very active woman before ME struck. It was in 1994 that I began having episodes of what the doctors labelled 'a virus,' and over the years they occurred more frequently until I was ill and exhausted most of the time. Early in 2001 I was diagnosed as having ME/CFS, and eventually had to give up work completely. I was a 'good patient' and tried all that my doctor, and various consultants recommended. Apart from Pacing, nothing helped, indeed some of the medications or 'therapies' offered actually made me much worse.

So I did what most of us do – tried everything else! I spent a fortune on homeopathy, magnet therapy, kinesiology, Reiki, crystal healing, reflexology, EFT, flower remedies, herbalism, energy healing, and even some acupuncture. I ate healthily, avoiding all chemicals. I was positive and cheerful and watched endless funny videos to boost my endorphins. I meditated, and had a full body massage every week to lessen the pain. I took supplements and vitamin pills. All helped in their own way by easing my symptoms, but I still remained ill without understanding why, and although I wasn't completely bed bound, I was totally reliant on others for help on a daily basis. I began to be afraid about what the future held for me.

Then I heard about Mickel Therapy. Dr David Mickel was a GP, who, unlike many others, did not believe his ME/CFS patients were 'depressed,' he could see that they were courageously coping with a very real illness with little support or understanding. He realised that ME is caused by a dysfunctional hypothalamus, which then creates the multitude of symptoms that make up ME. At long last, after years of meeting ignorance over why I felt so ill, a doctor was making sense of it all, and I felt immensely reassured. Dr Mickel then utilised proven, cutting edge, scientific knowledge to work holistically with his patients in order to heal this problem. And they got well!

The many testimonies on Dr Mickel's website were impressive, and I found Dr Mickel's attitude understated yet practical, so I decided to give this 'talking therapy' that is not psychotherapy, a try. From the very first session, I could feel that something had worked, over the next few months I grew in confidence, both with the technique itself, and with myself, as my illness subsided and my energy returned. What impressed me most was that I was being given the key to empower myself, and I was learning why all those other talking therapies had not worked for ME/CFS. ME is a physical illness, not a problem in our heads. Once we address the physical problem, not with medication or treatment that suppresses the 'message' within the symptoms, but in a holistic supportive, was, the body will respond appropriately and return naturally to health.

This, of course, challenges current medical beliefs, and what all of us have learnt from childhood, so it isn't easy to grasp at first. Yet absorbing and accepting this is definitely what helped me to heal. Life started to become fun once more. I even decided to do the training, and in January, all being well, I will become a Mickel Therapist. Just undertaking the travelling, never mind undergoing the training, was something I couldn't even consider earlier this year!

My path to full health has taken a few turns on the way and I'm still working on it, with Dr Mickel, using all that I've learnt, and am still learning. What I love about this treatment is that there is no blame or condemnation attached to being ill, there is only potential for greater understanding and compassionate healing, and more personal empowerment.

SUSIE

For those of you with internet access, there is more information at www.mickelreversetherapy.com and www.reverse-therapy.com. The former has a small trial of both therapies in young people in the news section. Other information on the web includes testimonials on <http://www.sleepydust.net> and an online diary of an ongoing experience at <http://reversetherapy.blogspot.com>.

I have a copy of Dr Mickel's book and Action for ME's article, which describe people's experiences, if you would like them. I can also give details of local practitioners. These approaches are expensive – at around £80 per session. If you decide to give it a try then do let us know how you get on (Jenny).

LYME DISEASE AND ME

Those of you who managed to get to the Black Swan for the October 8 meeting will have met member Lynn and heard her speak on the subject of Lyme Disease. This is a bacterial infection, often tick borne, which some believe has sometimes been misdiagnosed as ME. Lynn has kindly submitted this summary of her talk to the Newsletter.

I have lived with ME for over 17 years and have tried many expensive treatments to no avail. Thyroid treatment and antibiotics are the only things that have made any noticeable difference. As I felt such a huge improvement following six weeks of the antibiotic, Doxycycline, I have always suspected that my illness might be infection based. So in the summer of 2004 I attended the Lyme Disease conference in York to see if this might be the answer to my problems.

My blood was taken at the conference and observed under a microscope. Sure enough spirochaetes could be seen emerging from blood cells – it appeared that I was suffering from Lyme Disease (Borreliosis). Unfortunately GP's will not accept this – they require the diagnosis to be made on antibody testing and this is very unreliable. I knew that my GP would not be happy prescribing high dose, long term antibiotics and decided to try Samento, an improved form of the herbal medicine, Cats Claw. This seemed to be helping a number of sufferers so I thought it worth trying.

I started off at a low dose and built up to 15 drops twice a day. It has to be taken 30 minutes before meals and some form of detox must also be taken. This is a major problem as toxins caused by the bacterial 'die off' are as bad as the illness. This is probably the reason why so many of us think we can't tolerate antibiotics – they are actually working and we are having a 'Herxheimer' reaction. We need to drink copious amounts of water to flush out the toxins – I also used the herbal treatment, Mistletoe Leaf and this seemed to help.

Over the following 12 months I improved dramatically. The joint/muscle pain and swelling reduced, my fatigue all but disappeared and I was able to do something every day without resorting to resting between. However, my brain fog (memory and concentration loss) is still a major problem – I am considering taking fish oil/evening primrose oil to address this. Unfortunately, Lyme Disease is a difficult illness to both diagnose and treat. We need better testing methods and treatment regimes – diagnosis should be made clinically but this would demand a knowledgeable GP who could recognise the signs. I'm afraid that most know very little about this dreadful illness.

Anyone wishing to look further into Lyme Disease as a cause of their illness might want to look at the following web sites. I would particularly recommend the John Bleiwess paper 'When to suspect Lym..'

Eurolyme forum on Yahoo – excellent health discussion group (you will have to join). It provides a huge amount of information through their files and links sections on <http://healthgroups.yahoo/group/Eurolyme>.

When to suspect Lyme by John Bleiwess <http://cassia.org.essay.htm>.

Borreliosis/Lyme and ME/CFS in the United Kingdom by an ME sufferer www.drmyhill.co.uk/article.cfm?id=361.

Dr Burrascano Diagnostic Hints and Treatment Guidelines for Lyme and other Tick Borne Illnesses. This Doctor is a top American expert on all things Lyme and this excellent paper is essential reading particularly for our own GP's, www.ilads.org/burrascano_0905.htm.

Samento information www.samento-faq.tk/

LYNN



The deadline for contributions to our next Newsletter is
March 22, 2006



THE FRIENDSHIP NETWORK: A PERSONAL ACCOUNT

Hiya, I'M Kitty and I've been ill for 10 years, from 13 to 23. Susie asked me to write a little note to you all about the Friendship Network.

During the time I've been ill I've oscillated between being totally bed bound in the dark to being able to attend three half days at Sixth Form College and have a bit of a social life. Bit of a difference really! I've been severely affected for the last three years, bed bound mostly. When I relapsed I found this wonderful friendship network – plug for you Susie – and it has really brightened up my life!

I think the friendship scheme is especially useful when you are severely disabled as the beep of an e-mail, the telephone call or, in my case, the nice bit of post amongst the bills, is the best bit of your day! It can help with other's experience of different treatments; recommendations of health professionals in your area (if you are local to each other); guidance on educational opportunities; help with strategies to deal with friends or family; but most of all it just really helps to know you are not the only one with the problems you have – be they practical, familial or emotional. It is worth

writing to more than one person because between them I'm sure you will find someone who is going through the same thing as you.

The 'adverts' we put in the Newsletter can help to decide who would be best suited to you as a friend, but try and (cliché!) 'think outside the box'! We are all individuals and just because you are older, younger, a different gender, in a different family situation, doesn't mean you can't support and help each other. Sometimes a different perspective can help. Also because you have

this in common you can understand a wait between letters and e-mails or a very short phone call; which other friends may find difficult to understand.

So, anyway, my advice is give it a try – get some addresses from Susie and write to someone – it might make you life a whole lot more bearable! And if anyone would like to write to me I'd love some more post!

KITTY

FRIENDSHIP NETWORK



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 Susie Novis on 01723 374190

SAINSBURY FUND-RAISER
JANUARY 26
CAN YOU HELP?
This annual fund-raiser in York covers many of the day to day running costs of the Group
If you or anyone you know can join us for an hour, please give Jenny a ring

SCARBOROUGH MEETING

Group members in the Scarborough area are hoping to get together in the New Year. Details of the time and venue are not yet available, so either contact the ME line in the New Year, or the Group's website for details.



HOLY ROOD HOUSE

Holy Rood House in Thirsk is a centre for all kinds of people of all ages with a gentle Christian ethos. It has a reputation for good home cooking and a policy that no one should ever feel unable to stay because of cost. It offers a wide range of support including counselling, complementary therapies, and creative arts and has a special weekend each year to support people living with ME. For more information Tel 01845 522580 or visit the website at www.holyroodhouse.freeuk.com.



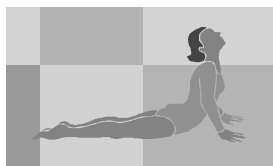
EXPERT PATIENT COURSES

These NHS courses, which help people manage chronic illness, will be available across our area in the coming year. For further details contact you local Patient Advocacy Liaison Service (see telephone book).

The Group's Website Address:
www.yorkmesupport.org.uk

YOGA SUITABLE FOR ME

Member, Helen, would like to set up or join a day class in the York area as her daytime Kripalu Yoga class, which she found very gentle, fun, relaxing and good for her body, has ended. If anyone would like to attend a new class especially suited for people with ME, or knows of a day class then please contact me and I'll pass on her details.



Helen has given me an interesting article by Angela Stevens, now on our website, which shows how people with ME can benefit from yoga, and also details her cassette tapes for people with ME/CFS who can't attend a class. One is on breathing, one is for people usually confined to bed and the other is for people with moderate energy levels. I have a copy of the article if you'd like it.

JENNY



PRIME

The Group continues to work to develop NHS services. We attended a workshop organised by PRIME, a project promoting partnership between people living with ME/CFS, carers, researchers and health professionals.



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
(Jenny)



volunteering - Can You Help

Would you like to be featured in a press article to raise awareness about ME?

If you can help please give Jenny a ring on 01904 655911 or e-mail:

jenny.gilmore@getreal.co.uk