



# YORK & DISTRICT ME SUPPORT GROUP

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

7 Glen Close  
Fulford  
York YO10 4PW  
Tel (01904) 655911  
(1.00-2.30 Monday-  
Thursday)

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## NEWSLETTER

## JANUARY 2005

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Hello everyone, and welcome to our January Newsletter  
We hope you have had a good Christmas and New Year

### **PUB MEETING**

We continue to meet for a social in the large downstairs front room at the Black Swan, Peasholme Green, York, on the first Wednesday of every month at 7.30pm. If you would like directions to the Black Swan, please give Jenny a ring on the York and District ME line (see above).

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### **PUBLICITY**

We have included more Information Cards about our Group for your local Post Office, Shop or Community Notice Board. This is part of our campaign to raise awareness about our group to give support to people with ME/CFS across the area that we cover.

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### **FUNDRAISING**

The group has received grants of £200 from the Norman Collinson Trust and £284 from the Purey Cust Trust to cover our newsletter and friendship network costs for the coming year. The group will need to raise more funds to cover other expenses and hope to organise a fundraising collection. Also, thank you to one of our members who has very kindly donated £100 to the Group.

### **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 Jenny on 01904 655911.

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### **WARM FRONT**

One of our members has contacted us to let us know that the grants for £1,500 (or £2,500 for the Over 60s) for insulating and heating for homes, etc, can include help with moving items, eg, clearing the loft. For more information contact the Energy Efficiency Advice Centre on 0800 512012.

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### **RESEARCH**

Luke, a student from York University, would like to know our views on the value of medicines for his PhD research. It would be a questionnaire that would take about half an hour either by telephone, e-mail or face to face. Please contact Luke on [lc182@york.ac.uk](mailto:lc182@york.ac.uk) or Tel 01904 433577 for more information.

This Newsletter is funded by Community Champions and York and North Yorkshire Community Foundation

# NEWS FROM THE GROUPS

Both Dr Charles Shepherds book "Living with ME" and Dr Anne Macintyre's book "ME: Chronic Fatigue Syndrome - A Practical Guide" (both RRP £9.99) are available at £10.00 each including postage and package to anywhere in the United Kingdom from the Sussex and Kent ME/CFS Society on **01273 778890**.

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**AYME** have produced a 30 page booklet titled "Surviving Severe ME" written by a 23-year-old with ME with additional information from AYME's professional advisors. Though at first sight it may seem expensive at £10.00 (plus £2.00 postage and package) it is very comprehensive and suitable for adults and younger people covering areas such as eating (including easy to eat foods), tube-feeding, washing and toileting, sitting and lying positions, pain/medication, sleep disturbance, pacing and activity suggestions. There are lots of useful contacts and Mail Order addresses. To obtain a copy please send a cheque for £12.00 to **AYME Ltd, "Surviving ME", Box 605, Milton Keynes, MK2 2XD**.

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**Thymes Trust** have published "Young Hearts", a fully illustrated collection of poetry by children and young people with ME with the forward by Terry Waite. They also have a new Professional Guide on their website - **The Special Educational Needs Co-ordinator (SENCO) Key Role in Supporting Pupils with ME/CFS**. It has been produced to assist SENCOs to manage educational demands on children with ME to preserve health and help them achieve. It incorporates some of the best ideas and practice

## MADE IN A DAY PROJECT IN PICKERING

Ryedale 50 Plus Forum is running creative workshops on April 14 at various locations in Pickering. It is free, lunch will be provided and free transport can be arranged. Activities are likely to include music, arts and crafts, creating ceramics, beauty therapy, cooking and using textiles. The day is particularly aimed at people who often don't have the chance to get involved in creative activity, such as older people and young parents and those facing a stressful time in their lives. For more information ring

**Action for ME** now has an online counselling service for people with ME. Clients who use the service can choose from counselling via e-mail correspondence or real-time private sessions with a counsellor using an instant on-line messaging service on a secure server. The new service can be accessed from the Action for ME website at [www.afme.org.uk](http://www.afme.org.uk) under "How We Help". It will be available free of charge for members of Action for ME during the initial one year trial. They have also produced a booklet on **pacing**. I felt a lot of it was very good - though it could have benefited from a few more practical strategies, example, on the best sort of diary to keep. It is available from Action for ME or on-line. (jenny)

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Dr Nigel Speight, who treats children and young people with ME in County Durham has joined the MEA as a Specialist Medical Advisor. (Jenny)

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Thank you to everyone who contacted me about Doctors and Therapists that you have found good. I continue to be asked for information so if you have any details that you would like to pass on them do let Jenny know on **01904 655911**.

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Action has been taken by Medical Services in Leeds as a result of our complaint about assessments by particular local doctors for Incapacity Benefit and DLA. We hope to continue to work with them to move towards a situation where all local people with ME/CFS undergo assessments that are fair and treat them with respect. It would be helpful for us to know how you have got on if you were assessed recently - please ring if you would like to talk about a medical that you have had. If you need to appeal against a decision it is important you get help - we can put you in touch with a local organisation that assist. Local organisations and the National ME organisations can also provide help and advice on completing forms. (Jenny)

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**THIS DOCUMENT IS AVAILABLE  
IN LARGE PRINT**

## YOGA

Thank you to Susie for letting us know about a Gentle Yoga Drop In Class (especially for those with limited movement, suitable for ME) at Scarborough Library, Monday, 2.45pm to 3.45pm, £3.50 per class, with fully qualified Yoga tutor Nikki Bailey. Inquiries, 01723 362989.

For those of you who can't attend a class the Yoga for Health Foundation have relaxation tapes specifically aimed for people with ME at around £6.00. The address is Ickwell, Bury, Biggleswade, SG18 9EF. Tel 01767 627271.

Web [www.yogaforhealthfoundation.co.uk](http://www.yogaforhealthfoundation.co.uk).

There is also a book for people with fatigue problems "**Beat Fatigue with Yoga**" by Fiona Agombar (Thorsons).

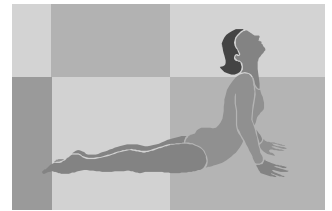
Websites include Angela Stevens' website [www.angela-stevens.co.uk](http://www.angela-stevens.co.uk). Sheffield Yoga for ME <http://www.sheffieldyogaforme.org> - [www.hopeproject.co.uk](http://www.hopeproject.co.uk).

## YOGA AND CHRONIC FATIGUE SYNDROME: PUTTING ENERGY BACK INTO YOUR SYSTEM

Unlike many exercise programmes, Yoga practice does not take energy away from the system, instead it puts energy back into the system. Contrary to most exercise programmes that leave you exhausted, your Yoga exercise period will leave you refreshed and renewed. When Yoga exercises are combined with breathing and meditation techniques, the Chronic Fatigue Syndrome patient has a daily support system that makes a productive life possible.

Here's how it works. Physical and emotional tension and fatigue lodge in muscle tissue, making it knotted, hot, and the circulation sluggish. Yoga exercises systematically stretch and relax the major muscle groups and push

fresh blood/oxygen through the tissues, which releases the tension and allows the muscles to relax and cool. The exercises are done slowly, and the breathing patterns with each exercise allow for maximum oxygen intake and for the release of toxins. Poor circulation also means the brain and other vital organs get less blood and important nutrients. Yoga exercises improve all over circulation by limbering the spine, by movements which improve elasticity in the blood vessels, and by selected inverted poses, which use compression to pump



more oxygen throughout the body. Breathing techniques improve concentration and awareness, and help to reduce stress reactions. Extreme reactions to stress - especially when they are triggered by a past event or a future fear, or by a situation that cannot be changed - cause energy demands to increase rapidly. Your breathing techniques put you in touch with an unlimited source of energy that lies within you. By constantly returning the mind to the present moment, you allow the body to deal with what's happening now. Relaxation and meditation teach conservation of energy and build self confidence. The student learns to completely relax every muscle in the body and then forget about the body while turning attention toward the mind in meditation. In meditation you simply stop all thought momentarily, allowing the strength within you to express itself.

*This article came from Immune Support.com sourced from the American Yoga Association.*

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## SERVICE DEVELOPMENT MEETING AND QUESTIONNAIRE

The Selby and York PCT ME/CFS Planning Group met towards the end of last year and are looking at ways forward following the failure of our bid for funding of a local service. I hope that you can complete the enclosed questionnaire by February 9 that will help with that process by giving an idea of the NHS services we're using.

Sue Pemberton, Clinical Champion, from the Chronic Fatigue Clinic in Leeds joined us at the meeting. She tells me that the Leeds Clinic is not taking new referrals from North Yorkshire until April, though their booklets advising GPs on caring for people with ME/CFS are still available. (Jenny)

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## MEDIA WATCH

**Horizon** (BBC, September 16, 2004). We have in this Newsletter given coverage to the beneficial effects of fish oil supplements. Accordingly, some of you may have been alarmed by this programme which outlined the danger of high intake of vitamin A, which occurs in oily fish and liver. The programme outlined the evidence linking high intake of vitamin A with a risk of bone fracture. However, the level of risk depends on what supplement is used. The website for 'Efamarine', one of the supplements we have mentioned, states "the oil does not contain elevated quantities of vitamin A and vitamin D as found in fish liver oils" ([www.efamol.com](http://www.efamol.com)).

Once again, **Dr Le Fanu**, the Sunday Telegraph's medical correspondent has returned to the subject of 'Sertraline' as a possible cure for ME (see last two Newsletters). He has now (*Sunday Telegraph*, November 21, 2004) heard from 27 ME sufferers who have tried the anti depressant, of these 10 either had to give up because of side effects, or had no improvement, 10 experienced a definite improvement, whilst seven were, in effect cured, one stating that he is now able to cycle from Leeds to York and back, a 50 mile round trip. If any of our readers have tried 'Sertraline' do please let us know.

**Barefoot Doctor Shoots Himself in Foot.** It is depressing when people who should know better still display a distressing ignorance on this subject. The "Barefoot Doctor" spoke about ME on Radio 2's **Johnnie Walker Show**, suggesting that people with the condition were using it as an opportunity to take "time out" and suggesting cognitive behaviour therapy as the best treatment.

*The Guardian* (November 13, 2004) warns that the Government is looking at ways of tightening up the rules for those on Incapacity Benefit. The Government is facing a looming pensions crisis and the £6.76bn per year Incapacity Benefit budget is under scrutiny. Apparently, this is what Tony Blair means when he talks of "re-configuring" the welfare system to "free up" resources. In other words, instead of financing pensions out of general taxation as in the past, they can perhaps be funded by attacking the meagre incomes of those unfortunate enough to be incapacitated (or perhaps I'm getting too political here).

The dangers of this are highlighted in the *Guardian* article by the case of Colin Baxter, who has ME and lives on Incapacity Benefit of £87.30 per week. "I had to keep going for medicals," Colin explains, "and because of the threat that benefits could be cut I pushed myself to try and do work. I came off the benefit, and I became more severely ill than ever. The last thing people need is the stress of having their benefits taken away, or being taken in for more testing."

There was a sensible and fairly optimistic piece on ME in the *Observer's* magazine of November 28 2004. It focused on Plymouth journalist Eleanor Pole who became ill in 2002, following a bout of glandular fever. This post viral condition felt, in Eleanor's words "like having to drag your body round all the time. Life became a massive struggle of mind over matter". Also, she reports, "I felt I was thinking through treacle." Sound familiar? Her GP eventually diagnosed ME, told her he'd seen many similar cases, but that "conventional medicine in the Plymouth area had nothing to offer." Why pick on the Plymouth area one is tempted to ask?

Like many sufferers Eleanor became her own expert and started to read on the subject and trawl through the internet. Ironically, according to the *Observer*, it's this drive to get better "incorrectly interpreted as a form of hypochondria" which has fuelled some of the medical scepticism about the condition. Eleanor herself, following a period of "almost total rest" and a carefully paced activity feels she has recouped 90% of her former energy. That makes her one of the lucky ones.

**BRIAN**

In a speech on *January 13*, **Tony Blair** confirmed measures were to be set out shortly targeted at those on Incapacity Benefit who require support to get back into appropriate work. For further information see [rightsnet.org.uk](http://rightsnet.org.uk). I think there is an understanding that not everybody on Incapacity Benefit can work, but we'll have to wait and see how the Government plans to proceed.

**JENNY**

## ACCORDING TO THE SCEPTICS . . .

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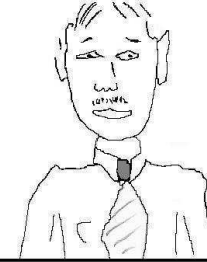
MMM - I'M MARRIED  
WITH CHILDREN, A GOOD  
JOB, AND A HOUSE ON  
A MORTGAGE

2



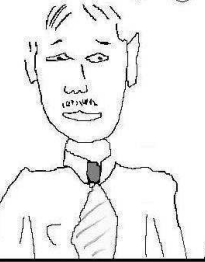
BUT I FANCY A BIT OF  
'TIME-OUT' - I THINK I'LL  
DO A FEW YEARS  
OF MALINGERING

3



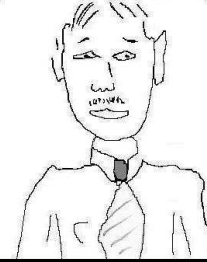
LET'S SEE - I NEED  
A SUITABLE ILLNESS  
TO FAKE

4



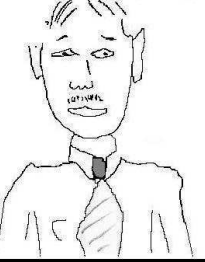
AH! CHRONIC FATIGUE  
SYNDROME - THAT SHOULD  
BE EASY TO FAKE - THERE'S  
NO TEST FOR IT

5



ACCORDING TO THIS  
LEAFLET I CAN  
CLAIM £80 A WEEK  
INCAPACITY BENEFIT

6



WOW! I'LL BE LIVING  
ON £80 A WEEK -  
THAT WILL REALLY  
PAY THE BILLS

BE



## VOLUNTEERING - CAN YOU HELP

Your help as a Volunteer would  
make a big difference to us

Either for a one off project, example, some research,  
finding out about fundraising, a display, etc, or a little bit  
of time to help us to help people with ME/CFS and their  
carers

If you can help please give Jenny a ring on 01904 655911

## E-MAIL ADDRESSES

For those of you on-line, it would really help us if you  
could please let us have your e-mail addresses

## STEP FORWARD

Courses for Women across North  
Yorkshire. They can offer help with  
confidence, assertiveness,  
employment opportunities, for women  
wishing to return to work or set up a  
business who are unemployed or  
working less than 16 hours a week.  
Travel costs and childcare funding are  
available. For more information ring  
the Craven and Harrogate Business  
Development Centre on 01423 853123.



# BOOK REVIEW

'The Great Thyroid Scandal and How To Survive It' by Dr Barry Durrant-Peatfield, Barons Down Publishing £12.99 from Amazon (or order from your local Library).

Dr Peatfield has treated ME/CFS for many years based on his view that the underlying problem is a down regulation of metabolism. This means that adrenal and thyroid insufficiency are at the root of the symptoms. His approach is based on research that has been available for 60 years. He says conventional medicine is still 'too entrenched in dogma and their own importance' to learn from it.

The main points he makes are:

1. If the thyroid is not fully functional nothing else will work properly;
2. He stressed the importance of treating both adrenals and thyroid simultaneously as both need the hormones the other produces to function.

Conventional medicine disregards the adrenals. This may be in part due to their reliance on the Synacthen test. In this test you are given an injection of the pituitary hormone ACTH which stimulates the adrenals to produce cortisol if this result is within the 'normal' ranges set they say your adrenals are okay. I have recently read elsewhere that this test is not positive until your adrenals have lost 90% of their function! If this is so, common sense suggests that your health will have suffered long before they are this bad!

A chapter on self help enables you to see if your metabolism is under active, by taking your basal temperature. This is your temperature at rest on waking first thing in the morning, before getting out of bed or doing anything else. Men and non menstruating women can take it any day of the month. If you are menstruating, days 2-5 of your cycle are the ones you can rely on. A temperature of 37C equals normal metabolism and thus normal thyroid function. 36.5C or below should raise suspicion of hypothyroid and taken together with other signs and symptoms is the basis of the diagnosis. Pulse rate is another helpful indicator normal basal pulse is 70-80 bpm.

Whatever the original cause of your ME/CFS it will have caused a chronic stress to your system and eventually the thyroid and adrenal function will be compromised. If your suspicions are raised do get the book and read it thoroughly. It is written for the non technical reader and Dr Peatfield gives instructions for treating yourself with natural glandular extracts available without prescription. You can use your temperature and pulse as a guide to your progress and for adjusting doses. This may help if your case is uncomplicated and your are confident to do so.

On <http://www.thyroiduk.org> there are articles by Dr Peatfield, one on adrenals and another that sums up his treatment approach. They also give details of a urine test for thyroid and adrenal hormones available in Holland. This can be done via thyroid UK without a doctor requesting it. Dr Peatfield considers this is the best available at present. Even so he emphasises that too much reliance must not be passed on laboratory tests, believing laboratory test results over the patient's symptoms is where conventional medicine has fallen down, with regard to diagnosis and treatment of thyroid and adrenal problems.

Two ME/CFS sufferers from York have recently consulted Dr Peatfield and are making positive progress.

Dr Peatfield can be consulted in person or by telephone. He does clinics around the country. For details ring or fax him on 01737 215462, or e-mail him at [info@drpeatfield.com](mailto:info@drpeatfield.com)

**SANDRA TOMLINSON**

*Treating ME/CFS using thyroid hormones is still very controversial with many doctors. I have articles by Dr Shepherd and Prof Anthony Pinching (Medical Advisers to the ME Association and Action for ME) and a response by Dr Peatfield if you would like them. If you are trying or have tried this approach the Group would be very interested to hear how you are getting on.*

**JENNY**

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