

YORK & DISTRICT

ME

SUPPORT GROUP

YORK & DISTRICT ME SUPPORT GROUP

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

e-mail: enquiries@yorkmesupport.org.uk

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Tel (01904) 655911
(1.00-2.30 Monday-
Thursday)

NEWSLETTER

APRIL 2006



Farewell message from your chair

Hi everyone. Apologies for the delay with our newsletter. It's with a lot of sadness that I write to let you know that I am leaving the role of Chair at our AGM. I will continue with ME line until the 24th May. From then our new contact will be Sandra on 01347 810841. The opening hours of the line will stay the same, but it will be closed from 6th June for 10 days. I plan to stay involved with the group, predominantly helping with service development and hope you are able to join me for a drink and snack at our AGM. It's been lovely talking to you all over the past 3 years - thank you for all your support. Best Wishes Jenny

Agm/group meetings

The Group is meeting in Scarborough for ME Awareness week (see below) and at 7.30 pm on the first Wednesday of each month in York, **except in May**. In August there'll be no meeting.

AGM & Social

Wednesday May 10, Jenny's home, 7 Glen Close, Fulford, York. 7.30 pm

Would be great to see you if you can join us for a chat and to elect our new Committee.

Social Meeting

June 7, Black Swan, Peasholme Green, York. 7.30 pm

Opportunity to learn more about reverse therapy & MICKEL Therapy

July 5, Reverse Therapy at Jenny's home at 7 Glen Close, Fulford, York 7.30 pm

We are arranging meetings about these 2 new controversial approaches for treating CFS/ME and Fibromyalgia during May or July. Reverse Therapist Andy McGregor is joining us in July. Mickel Therapists Susie and David are yet to confirm, so please get in touch if you would like to meet them or, check our website.

Thyroid and Adrenal Update

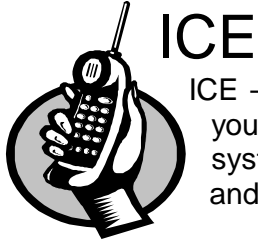
September 6, Black Swan, Peasholme Green, York. 7.30 pm

***** Scarborough Meeting *****

We hope to see you for chat and a drink in Clifton Hotel's lounge, overlooking the sea and castle.

May 8, Clifton Hotel, Queen's Parade, Scarborough. 1- 2.30 pm

There is car parking and disabled access at all our meetings, but do call our ME line if you would like more information.



ICE – In Case of Emergency – is a new idea for putting family contact details in your mobile phone address book. All the emergency services recommend this system. So, just type in ICE as the name to be stored in your mobile phone book and then put in the emergency contact details.



MANAGING MONEY PROJECT

The York Citizens Advice Bureau is running a free training course, suitable for people on a low income to help them develop better money management skills. The course consists of four (two hour) sessions and will cover subjects such as budgeting, debt and credit. For further information contact Nikki, Humberside and York Citizens Advice Bureau on 01904 623648.

NATIONAL ME AWARENESS WEEK

National ME Awareness Week is approaching! It's May 8 2006 to May 14 2006 for those who have not yet got it in your diary. YDMESG are already thinking about how to raise awareness in the local newspapers throughout our area. **If you would like to be featured in a newspaper article about how ME affects you and help us to correct some of the myths about ME, then we want to hear from you.**

We are in particular need of people to feature in Selby, Whitby, and the area covered by the Northern Echo. If you are interested then please call the helpline – 01904 655911 (Monday to Thursday, 1.00pm-2.30pm) or e-mail publicity@yorkmesupport.org.uk.

We would also like to hear about any fund or awareness raising activities you are planning for ME week. If you let us know then we'll see if we can help you get your activities in the press. There are lots of ideas in March's edition of Interaction from Action for ME if you are stuck. Log on to <http://www.afme.org.uk>.

ME AWARENESS WEEK EVENTS

NATIONAL CONFERENCE – MAY 12 – LONDON

An update on Clinical Diagnosis, Research Trends and Educational Support
Speakers include Jane Colby,
Professor Basant Puri,
Professor Malcolm Hooper
(Sunderland University) and
Doctor Byron Hyde
(Nightingale Research Foundation, Toronto)

ME PEOPLES DAY RALLY – MAY 12

Outside Department of Health to launch a petition on Science and Research Based Healthcare Policy for ME (see also www.petition.me.uk)

ME FREE FOR ALL

Is a programme for ME Awareness Week (see www.mefreeforall.org).

HEALING

The National Federation of Spiritual Healers runs weekly hands on healing meetings at the Friends Meeting House in York, Thursday, 7.15pm to 9.00pm, £3.00 or more donation to cover the costs of the room. Our member, Anne-Marie went along: 'There was a guided meditation, which I found very relaxing and the healing itself made me feel warm and got rid of a lot of tensions and pains.' Contact Mr J Phelps 01423 359241, web: www.nfsh.org.uk.

JENNY

COMPUTERS

Free computer equipment from Leonard Cheshire Workability Scheme for 16-55s. Successful applicants do a short computer course and pay computer delivery costs. It is hoped that this may eventually lead to paid or unpaid work or some kind of further education, so you can apply even if you are quite restricted at the moment. The computer which I use for the Support Group came from this scheme about five years ago and has been an enormous help. Member Madelaine, who has recently got her computer equipment, is looking forward to starting her course. Check out www.leonardcheshire.org or telephone 020 7802 8200

JENNY



COMPUTER PROBLEMS

It can be difficult to find someone to help if you have problems with your computer. One of our members recommends Mark, who can visit you if you are in the York area. She says he's very good, and extremely reasonably priced. Contact 01904 767055, or e-mail mark@mittas.co.uk or web <http://www.mittas.co.uk/>.

ITCH network (<http://www.itcanhelp.org.uk>) can provide computer volunteers to help with problems, though unfortunately has none in our area at the moment.

Abilitynet (<http://www.abilitynet.org.uk>) Freephone Helpline 0800 269545 provides advice, factsheets, assessments, training and assistive technology to help people with disability. Their site includes a link to 'my computer my way' resource on-line to help you learn about the various specialist assistive technologies that are available for the PC, eg voice activated software.

JENNY



yellow card

A yellow card is what a football referee shows to a player who has infringed the rules. Presumably that is where the MHRA (medicines and Health Care Products Regulating Agency) got the name for its new system of reporting side effects of medicines and herbal remedies. If you wish to report a side effect, or are worried about a suspected side effect you can ring them on 0808 100 3352, and they will send you a leaflet incorporating the said yellow card for you to complete and return (freepost) or see www.yellowcard.gov.uk.



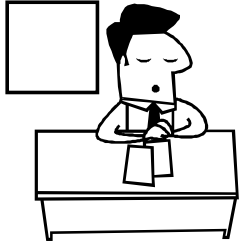
SHOP MOBILITY SCHEME – SCARBOROUGH

This is located at 5 Somerset Terrace to the rear of the Brunswick Centre, where there is car parking. Users should ring in advance (01723 369910) and bring some identity. Powered scooters are available from £2.50 per day. See web www.shopmobility.uk.com.



The deadline for contributions to our next Newsletter is AUGUST 16,
2006

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

Radio 4's *'Check Up'* programme has recently covered the subject of ME/CFS and not surprisingly found itself 'overwhelmed' with calls and e-mails. Professor Leslie Findlay, of the National ME Centre, Essex, was in the studio. He said that treatment for ME has to be tailored to individual patients as the term 'ME' covers a 'heterogeneous group of disorders, patients have a wide variety of symptoms.' In response to a caller who complained of her GP's disbelief, the Professor maintained that 'enlightenment (in the medical profession) is growing exponentially,' However, he could see no 'quick fix pill' for the condition in the foreseeable future. Patients, he said, need to see 'a good specialist with a supportive multi-disciplinary team.' As far as graded exercise is concerned, Professor Findlay felt it was only suitable for those with 'relatively mild ME.' For others, 'we use activity programmes using rest and activity in a structured format to re-establish normal patterns of functioning.' He warned too, that there are 'plenty of people peddling remedies which have no logical basis and are expensive.'

Also on Radio 4, *'You and Yours'* had a phone-in on Incapacity Benefit on March 28 with Secretary of State for Work and Pensions, John Hutton. The programme added further confusion on the subject of the total number claiming the benefit (see article) with the claim that 1.7 million are 'receiving the benefit.' John Hutton, in the programme, promised reform of the Personal Capability Test in response to an ME sufferer who felt that the doctor carrying out her medical 'had not understood at all her condition.' 'Fluctuating conditions like ME are the hardest to measure, and we are working very hard to find a better way of doing that,' the Secretary of State maintained. It may have been a comfort for current Incapacity Benefit claimants to hear John Hutton say 'the reforms we are proposing are for new benefit claimants. It is very important not to lose sight of that: people, after 2008, who come into the new system. We are not changing the position or the way people are treated in the current rules.'

BRIAN



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



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)

RETURNING TO WORK – THE HELP AVAILABLE

As promised in the last Newsletter, an outline of the help available for those on benefits who are fortunate enough to consider a return to work.

PERMITTED EARNINGS

Someone on Incapacity Benefit or Income Support on health grounds, is permitted to earn up to £20.00 per week without their benefit being affected, for an indefinite period. If you are on Incapacity Benefit you can also earn up to £81.00 per week and work less than 16 hours per week (on average). You can do this for up to 52 weeks. If you want to start work under the permitted work rules, let the DWP know using form PW1 obtainable from them.

PROTECTED BENEFIT

An Incapacity Benefit claimant can have their benefit protected for a year while they try to return to work. In other words, if you attempt to return to work, but find that you cannot manage, you can, within a year, return to your benefit at its existing rate, without any medical test. The aim here is to prevent the fear of losing benefit becoming a disincentive to attempting to return to work.

PERSONAL ADVISORS

The DWP employ 'Incapacity Benefit Personal Advisors' with whom it is possible to discuss the issues of returning to work and benefits. If you live in the Ryedale area Tel 01653 685818 Monday, Thursday, Friday; if in York, Tel 01904 682141 or 01904 682192. The DWP assure me that approaching them to discuss you situation with definitely not trigger a medical review. However, there is an alternative source of advice on these issues that is not connected to the DWP. See box on the right Benefits information on this item from York Job Centre Plus to www.jobcentreplus.gov.uk.

BRIAN



FUNDRAISING

A group of young volunteers are providing bag packing services at Sainsburys at Monks Cross, York, on April 20, from 9.30am for ME Awareness Week and to raise funds for Action for ME, AYME and the Group. Many thanks to Nicola and her daughter for all their hard work with this event – I know they would love to see you there if you would like to support it. Thanks to all you assisted at the Sainsbury's Fundraiser on January 21. We raised £258.40 for the Group.

JENNY

THE DAWN PROJECT

The DAWN Project supports and assists people with a health issue or a disability, looking at learning opportunities or work options. Our team consists of Learning and Work Advisors, Job Coaches and Mentors. We work alongside employers and in partnership with other organisations to provide the best opportunities for each individual. We aim to accommodate each individual's needs and can arrange one to one appointments and external visits as necessary. We can provide free information, advice and support with:

- *Producing a CV, writing applications, job searching and interview techniques;*
- *Finding courses and looking into what support may be available;*
- *Looking for voluntary, part-time or full-time work;*
- *How working might affect your benefits.*

MARK CRAVEN
Future Prospects

Mark Craven can be contacted at Future Prospects, 24 Swinegate, YO1 8AZ. Tel 01904 634748 or Freephone 0800 834239. See also www.futureprospects.org.uk.

THIS DOCUMENT IS AVAILABLE IN LARGE PRINT

SERVICE DEVELOPMENT

As you may be aware the North Yorkshire Primary Care Trusts (PCT) responsible for much local NHS care and service development are to amalgamate this year. The resulting PCT will have debts, as some areas, particularly Selby and York, are ver much in debt. The exact impact of the changes is unclear. Members have attended meetings about this change in York and Scarborough on behalf of the Group and three of us met with the Selby and York PCT.

Existing arrangements with the Leeds Clinic and in York are to continue and there is a new ME specialist working in Harrogate. I went to an ME/CFS NHS Conference on the new NHS services that have started in other parts of the United Kingdom as a result of the £8.5 million investment a couple of years ago. It provided a good opportunity to see what was happening elsewhere, especially in rural areas. I hope to continue to work to improve things here.

The Evening Press announced a £500,000 AFME sponsored lottery grant to find out more about the causes and effects on ME/CFS on people's lives in Hull and York. Medical school is involved. We hope to have more information in a future Newsletter.

JENNY



incapacity benefit – the numbers mystery

In all the recent debates on Incapacity Benefit, a figure of 2.7 million claimants has been used both by the media, and by Government spokesmen. Readers may recall that in our Newsletter a year ago we queried this figure. Further doubts about the 2.7 million figure have now been raised by the Disability Consortium, an umbrella organisation involving the TUC and leading disability charities, including MENCAP, MIND, Scope Age Concern and the RNIB. On their website (www.disabilityalliance.org) they state that the 2.7 million figure is:

'The number of people who claimed Incapacity Benefit, not the number receiving it. Not everyone is successful, some fail the medical test, others have not paid sufficient National Insurance contributions.'

They further state that:

'The number of people getting Incapacity Benefit has fallen by 22% since 1995 and is now 1.44 million (February 2005).'

We can understand that the Government could legitimately include in its total figure both those who receive Incapacity Benefit itself, and those awarded Income Support with exemption from signing on as a Job Seeker because they have made insufficient National Insurance contributions. What would be harder to understand would be the inclusion in the total figure of 'claimants,' those who had 'claimed' Incapacity Benefit in the sense of having applied for it, but were turned down because they failed to meet the medical criteria. This seems to be what the Disability Benefits Consortium are maintaining.

There is a huge and puzzling gap between the Government figure (2.7 million) and the Disability Benefits Consortium (1.44 million). Furthermore, if the number claiming Incapacity Benefit are falling as steeply as the Disability Benefits Consortium maintain, why has reducing the numbers claiming Incapacity Benefit assumed such political importance?

BRIAN

LIBRARY DISPLAY

**There will be a display on ME in the York Central Library from Monday,
September 11, for one week**

NEW WEBSITE

The web address www.northyorks.gov.uk/iffy is for information for Families and Youth (IFFY). This is a free local database and website featuring organisations and groups for families, children, young people and the elderly. Manager Lynette Dodds says: 'Although there are hundreds of organisations that provide services that range from Homework Clubs to Bereavement Services across North Yorkshire, there hasn't been a website that gives you all the information on what is available. This is what county wide IFFY will achieve.'

