





the Leeds Group, Tel 0113 298 2070, or on-line at <http://www.ldmeg.org.uk>.

## **BENEFITS**

### **RECEIVING YOUR FULL STATE PENSION**

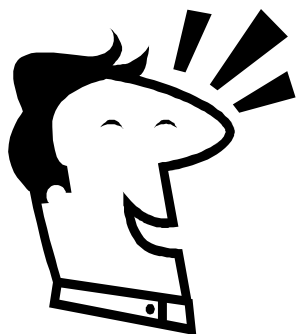
The Group has received a couple of calls from members who have been told they are not entitled to receive the full state pension unless they pay considerable amounts as they have not paid enough national insurance contributions. Contributions are usually paid by the state when people are ill as part of benefits. For one member this payment hasn't happened. Another did not claim benefit when first ill as she wasn't entitled. Neither realised they would need the contributions paid to get the full state pension.

The Pensions Office has advised that pensioners are entitled to a minimum income, the same as the state pension. This is, however, means tested, so some people may receive little or no financial help from the Government when they reach retirement age. They inform me that to claim the full state pension women need to have contributions for 39 out of 44 years and men 44 out of 49 years from age 16. Even one missing week for a self employed person in a year can negate the whole year.

To receive a pension forecast ring 0845 3000 168. If you find this affects you then do let us know. This is a concerning issue that we may need to look at on behalf of our members (Jenny).

### **AN INDEPENDENT MEDICAL ASSESSMENT**

David has let us know that Dr Wood, Consultant Immunologist at the Chronic Fatigue Clinic in Leeds, will do a consultation and a letter for the Benefits Agency for £125. Dr Wood needs a letter from your GP and advises a diagnosis of CFS from the Chronic Fatigue Clinic first helps in his diagnosis. Your Benefits Agency forms should say you are seeing an independent specialist for assessment. For an appointment Tel BUPA Leeds 0113 218 5908.



## **FREE LIFE COACHING BY GROUP MEMBER SUSIE**

I have just passed my Certificate in Life Coaching, and am starting on my Diploma - for which I will need people to work with

These sessions can be undertaken either face to face, or by telephone, and of course there is no charge whatsoever - just a commitment to the process, if it feels right for that person

Life Coaching is a very practical reality based approach that can help us move on from feeling stuck and unhappy, and into our full potential, our biggest dreams - whatever they may be

I've undertaken Life Coaching myself, and have found it to be a wonderfully empowering and eye-opening process

**If anyone wants to know more, they can Telephone me on 01723 374190  
(Susie Novis, Scarborough)**

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**THIS DOCUMENT IS AVAILABLE IN LARGE PRINT**

**INCAPACITY BENEFIT - SO WHAT IS HAPPENING?**

On February 2, Alan Johnson, the Work and Pensions Secretary announced a new regime for Incapacity Benefit. This will not come into force until 2008, and will only apply to new claimants (or at least 'initially'). The main points are:

- Incapacity Benefit will be split into two new benefits;
- The less sick will initially be paid at an equivalent rate to the Job Seekers allowance (£55 per week at current rates) until they face a medical assessment - hopefully within 12 weeks;
- The majority will receive a Rehabilitation Support Allowance of about £75 per week, however this will be reduced by £20 per week if they do not take steps, including regular work focused interviews to get themselves back to work;
- The more sick - an estimated 20% of applicants, will get a new benefit of more than £80 per week;
- An extra £20 per week premium will be payable to those joining a New Deal programme to help rehabilitation, training and finding work.

Many on Incapacity Benefit will find all this worrying enough, but it is not nearly as draconian as some of the inaccurate speculation that has appeared in the press - for example that Incapacity Benefit would be only payable for six months. Maybe this is cynical, but it seems a regular Government tactic to leak inaccurate information of a draconian nature in advance of new legislation, so that when the final plans are revealed and prove to be not as bad as feared they are greeted with sighs of relief rather than protest.

Also inaccurate are some of the statistics which have appeared in the press - especially that Incapacity Benefit is claimed by 2.7m people - a figure that was repeated in the Commons by the Conservative's David Willetts. There seems to be some confusion over the term 'claimed.' The 2.7m are those who have claimed Incapacity Benefit in the sense of having applied for it. Those who actually receive it number, according to the Disability Alliance 1.47m people. There has also been a 21% fall in the number of people on Incapacity Benefit since 1995, hardly the impression given by some politicians and journalists, who have depicted Incapacity Benefit as being out of control.

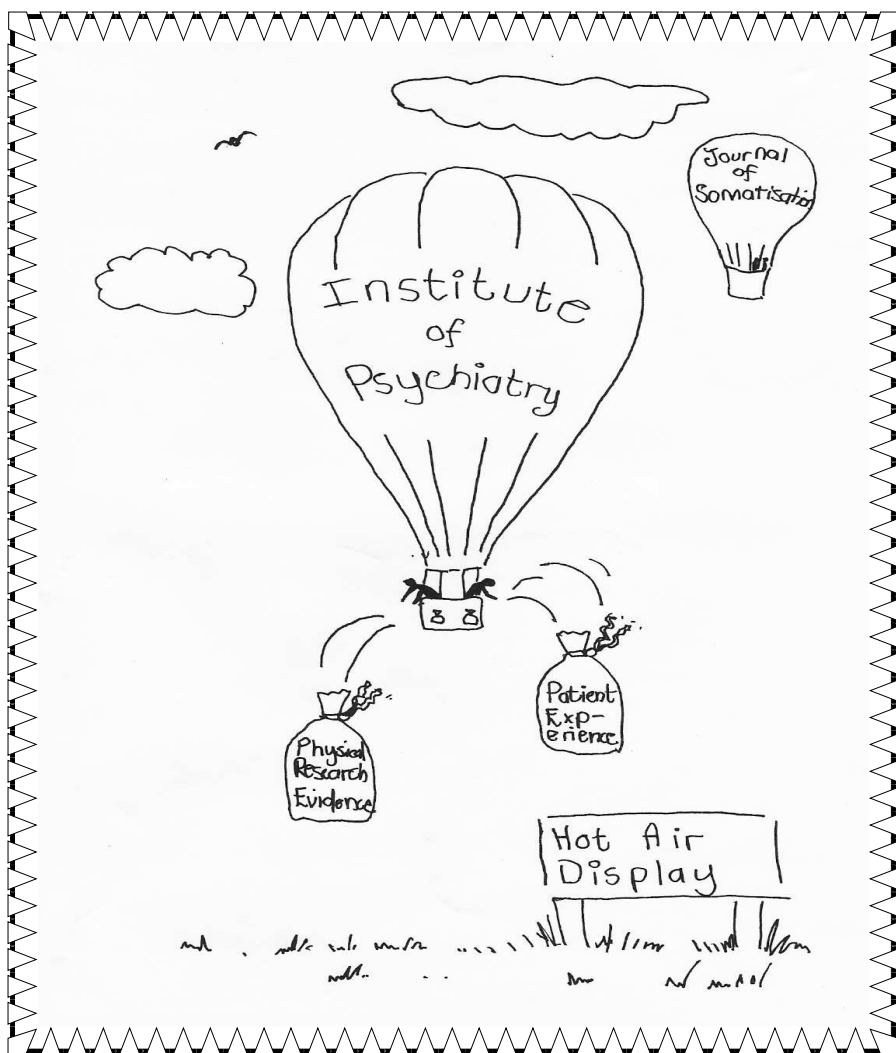
**BRIAN**



**CINEMA CONCESSIONS/DVD HIRE**

The Cinema Exhibitors' Association (CEA) has a new card that entitles a disabled person's companion to a free cinema ticket. To qualify you must be in receipt of one or more of the following: A Disabled Person's Railcard, Disability Living Allowance, or Registered Blind. The card costs £5 and is valid for three years. You can apply by telephone 0151 348 8020, e-mail [applications@ceacard.co.uk](mailto:applications@ceacard.co.uk), download an application form from [www.ceacard.co.uk](http://www.ceacard.co.uk) or request a form from your local cinema.

For those online it is now possible to rent films online. Check out [www.blockbuster.co.uk](http://www.blockbuster.co.uk). You can rent films free for a month. Apparently there's no catch so long as you cancel the subscription at or before the end of the free 30 day trial. Tesco have a similar service at [Tesco.com](http://Tesco.com) from £7.97 per month.



**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](mailto:jenny.gilmore@getreal.co.uk)

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**USEFUL CONTACTS**

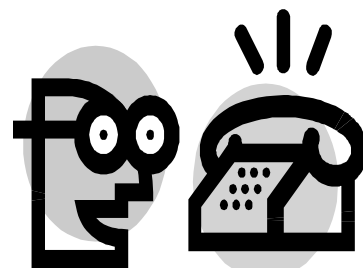
The Selby and York Carer's Centre which provides information and support for carers and on a wide range of topics, eg, benefits, advocacy, home care and special support for young carers has changed its contact numbers

From April 2005 York Vale Carers are beginning Coffee Mornings in Selby and York

For young and adult Carer's Services they are now York 724466 and Selby 724314

**UNWANTED CALLS**

You can stop unwanted telephone calls from salesmen, etc, via 0845 0700707, or you can register your number at [www.tpsonline.org.uk](http://www.tpsonline.org.uk)



I have been on it for two to three years and have found it an excellent service (Jenny)

## **SERVICE DEVELOPMENT**

Thank you to everyone who responded to our survey on NHS care - it is invaluable to us to be able to feed members experiences into the service development process. Key issues identified were:

- People with ME/CFS were accessing NHS care which was ME related, eg, lifestyle management in Leeds and York, flu jabs, medication for pain management, investigation of gut problems, tinnitus, or unrelated to ME, eg, management of diabetes, back problems;
- The 22 respondents had visited the GP 46 times and Consultants 18 times (10 visits to a Consultant were by one member for a condition unrelated to ME);
- Often individuals don't visit their GP often as they can offer little;
- Sometimes individuals have to cancel, or not attend appointments because they are too unwell, they are often concerned that their needs won't be understood;
- Some people are still treated inappropriately by professionals;
- People find specialist care in Leeds and York helpful, but access can be difficult or impossible;
- NHS care of all types for the very severely affected can be unavailable or take a long time to access.

We have fed these issues, plus other key issues to the Selby and York Primary Care Trust. Other issues include the need for early diagnosis and appropriate advice on illness management to where possible minimise severity and the length of time it lasts. We are continuing to work to encourage local Primary Care Trusts to provide accessible care (either at home or at an easy to get to community base) provided by health professionals with specialist knowledge of the needs of people with ME/CFS.

The Selby and York PCT have advised us of two new Government led initiatives for people with long term medical conditions which may help the provision of care to those of you with the severer forms of

## **ME AWARENESS WEEK**

**MAY 9 TO MAY 15**

On May 12 the ME Alliance will launch a new report to the media. ME Diagnosis: Delay Harms Health. Other events planned include a presentation to 10 Downing Street and a demonstration outside the Department of Health. There is an on-line poll on diagnosis at Action for ME's website.

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## **THE LYME DISEASE ACTION CONFERENCE**

**SHEFFIELD - JUNE 17 TO JUNE 18**

The Conference will look at diagnosis, treatment and possible links between these tick borne infections and chronic illnesses such as ME. Speakers are from abroad and the UK and include Dr Vance Spence and Dr Andrew Wright, GP Chronic Fatigue clinician and researcher. For more details see [www.lymediseaseaction.org.uk](http://www.lymediseaseaction.org.uk) or contact Jenny. Details of last year's York conference are in our August/September 2004 Newsletter.

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## **CHILDREN'S UPDATE**

In February the Royal College of Paediatrics and Child Health launched guidelines on management of ME/CFS in children and young people, for distribution to paediatricians in the UK. Generally seen as a step forward, they do not go as far as the ME organisations would have liked particularly in terms of care. Also, the research by Dr Barry Wright and Dr Beverley from Limetrees in York on children's treatments has now been published. For more information contact Jenny.

ME. Changes include a new type of health professional, the '**Community Matron**' who will be employed by 2007 to give one-to-one support to people in the community. They will monitor health and co-ordinate the care and support people need to achieve a better quality of life.