

## OMEGA NEWSLETTER JULY 2009 Vol 66

This Newsletter looks a bit different from usual. This is due to a combination of holidays and glitches (both health and technical). So no pics this time... We all keep reminding ourselves that we can only do what we can do. I'm sorry we haven't yet been able to publish the many articles you have sent. We have enough for two further editions, so watch this space!

Meanwhile, we bring you an account of the very useful talk about the Benefits system given at the AGM (p2). Many of us with ME are entitled to benefits of one kind or another and while OMEGA cannot give advice about this, there are people who can (p4). Many of us find Disability Living Allowance particularly difficult to apply for (with the long application form and the depressing emphasis on what one cannot do). These benefits are there to make life a little bit easier for us (to pay for extra help, or for getting about) and we urge you to get advice about applying. In the same way, we cannot take up individual cases if any member has a concern about the NHS, so (p6) there is information about that.

We will have a full account of the AGM next time; one important item was the heartfelt vote of thanks to Lewis for all his careful work in looking after the money for us over the years. We are very grateful indeed to him and to Barbara for taking care of publicity and preparations for meetings. Their quiet and capable work has enabled our meetings to be well attended and run smoothly. A big Thank You from us all.

We can also announce that Helen Garfitt has agreed to look after the subscription income for us. So if you haven't yet paid your subs for this year please now send it to Helen (full details on p6). We are very grateful that Helen has taken this on.

Another very good piece of news is that we now have the help of several volunteers, recruited at the Oxford Brookes Volunteer Fair which some of our members attended on your behalf in February. Mary Horan is helping us with our administration, and designed several successful posters for us. With Mary's help we will be able to do so much more. Kim Francis is designing a website for us. Your committee has seen the need for this for ages and we are very pleased that Kim is working on this for us. We feature our two volunteers in the Getting to Know You column this time (p6). The website address will be [www.oxnet.org.uk/omega](http://www.oxnet.org.uk/omega) Watch this space!

**Our Summer social event is the Annual Picnic on 8 August in Florence Park, Oxford (details on p4).** On the back page there are also details of Jan's monthly meditation classes and the various social meetings in different parts of the county. All are welcome to any of these gatherings.

Would you like to edit this Newsletter, maybe for a one-off as a guest editor? We have a great production team but we still need help on the editing side.

Patricia Wells, Editor for this issue.

## **The Benefits System** **Summary of Talk given at OMEGA AGM 28 March 2009**

Our speaker, Judy Gay of Oxford Citizens Advice Bureau, guided us through the complexities of the benefits system. We are very grateful to her. What follows is a brief summary. To read the full talk see below.

Judy said that she found people often reluctant to claim benefits to which they were fully entitled as they felt there was a stigma to this. She pointed out that there are two benefits that everyone gets. These are Children's Allowance (if one has children) and the State Pension (if one is old enough).

There are two types of benefits: **Means-tested** where your income from most sources and that of your partner (if any) and your joint capital (though not the house you live in) is taken into account. For **non-means-tested benefits**, there may be conditions to do with your earnings, and other conditions such as National Insurance contributions, age or fitness for work, but your income and capital is NOT taken into account.

**Non-Means-Tested Benefits** include **Disability Living Allowance (DLA)** for people under 65 who need extra help because of their illness/disability. There are two components: the Care component for someone who needs help with personal care, (there are three rates) and the Mobility component for those who have difficulty with walking (there are two rates).

**Attendance Allowance (AA)** is similar to DLA for people over 65 though there is no entitlement to the Mobility component.

Neither of these benefits are taxable and they do not depend on National Insurance contributions.

**Carer's Allowance (CA)** is for carers i.e. for a person looking after someone who is in receipt of AA or the middle or higher rate of care component of DLA. There are some conditions.

**Incapacity Benefit (IB)** for people who cannot work because of illness or disability. New claimants need to claim **Employment and Support Allowance (ESA)**.

**ESA** is a new benefit introduced in October 2008, replacing IB (above) and Income Support (below) paid on the basis of incapacity for work for new claimants. Can be claimed either on the basis of National Insurance (NI) contributions, or income related, or both. A new definition 'limited capability for work' means they qualify for ESA not that claimants are expected to work. Further tests divide claimants into 'work-related activity' and 'support' groups after a 13-week assessment phase. Income-related ESA may be paid to those without enough NI contributions, or who have extra needs or a mortgage. (See under **Income Support**).

**Bereavement Benefit** may be payable on the death of a legal spouse.  
**NHS Benefits** some claimants may be entitled to exception from prescription charges.

**Means-Tested (Income-related) Benefits**

**Child Tax Credit (CTC)** for most people who have dependent children, payable as well as Child Benefit, amounts vary with age and number of children and income of parents. In new claims CTC replaces amounts formerly included for children in IS calculations.

**Working Tax Credit (WTC).** Payable to working people on a medium to low income, depending on age, children, disability and number of hours worked.

Both **CTC** and **WTC** are administered by the Inland Revenue.

**Income Support** for people under 60 not working more than 16 hours per week and who may be sick or disabled (new claimants claim **ESA**), lone parents, carers some other categories such as disabled students. Anyone not in one of these categories needs to sign on for work at a Jobcentre and claim **Jobseeker's Allowance**.

**Pension Credit** replaces Income Support for people over 60.

**Housing Benefit and Council Tax Benefit** for help with rent and Council Tax can be claimed whether working or not. Administered by the local authority (wherever you pay your Council Tax).

**NHS Charges** – people on Income Support, Guarantee Pension Credit and some levels of Tax Credits automatically get free prescriptions and maximum help with dental charges and paying for glasses. Others on a low income can apply for help on an HC1 form.

**The Social Fund** provides grants and loans for some one-off expenses like Winter Fuel Payment, cold weather payments, funeral payments. Sure Start maternity grants may be available. There are other discretionary grants and loans.

Judy took questions and advised some members individually after her very informative talk.

If you think you may be entitled to any benefits (and many OMEGA members are, one way or another) we urge you to seek advice. If you find it hard to manage it is well worth talking to someone. For example, many people with ME are entitled to claim DLA. If you find it hard to cook a meal or have difficulty with walking it is well worth applying. The forms are complex and, most ME people find, quite depressing to fill in, because they ask what one cannot do. [OMEGA recommends getting help with filling in the forms.](#)

Even from this brief summary you can see that the benefits system is complicated and hard to understand. There are several different qualifying criteria for different benefits. To read the full text of the talk with full details of these benefits and the current amounts for each of them email us at [newsletter.OMEGA@googlemail.com](mailto:newsletter.OMEGA@googlemail.com) or for hard copy ring Lesh on 01865 766310.

## **Sources of advice and information about benefits include**

### **DWP (Dept of Work and Pensions)**

Benefit Enquiry Line: 0800 88 22 00 advice for people with disabilities and their carers. They will also send out individual dated forms for AA and DLA

New claims for under 60s - ring 0800 055 66 88

Pension Credit - application line 0800 991234

### **Advice Agencies**

Citizens Advice Bureaux - in most towns, listed in phone book. Some GP practices in Oxford City have outreach CAB sessions under the Benefits in Practice scheme.

Age Concern - for over 55s. 01235 849400

National patient groups Action for ME (AfME) and ME Action (MEA) have specialist benefit advice teams.

Local Advice centres e.g.: Agnes Smith Advice Centre, tel: 770206 96 Blackbird Leys Rd., Blackbird Leys, Oxford, OX4 6HS

Barton Information Centre, tel 744152  
Underhill Circus, Barton, Oxford.

## **OMEGA Annual Picnic**

**Saturday 8th August from 12.30 onwards**

**In Florence Park, Oxford (near the bandstand)**

This is a great opportunity to chill out with fellow ME people, friends and carers. All are welcome. Please bring lunch (we usually share) and something to sit or lie down on. If it is raining we shall shelter in the bandstand.

### **Directions:**

From Cowley Road turn into Littlehay Road (near the Q8 Garage) Take the first right into Rymers Lane. Follow the road alongside the park to the last gate (opposite the allotments). You should be able to see the bandstand from there. There is space to park in the road.

## **Report from the Clinic Group July 2009**

We have realised that some members do not know what the Clinic Group does so we thought it would be good to tell you more about it. Here is what we hope is the first of regular updates on our work.

The Clinic Group started 10 years ago and many different people have been involved over the years. It is the most active Omega Group. When we started there was no NHS treatment available for people too ill to get to the John Radcliffe Hospital in Oxford, or for young people, or for people who did not just want psychological approach. GPs knew a lot less then about the illness.

The early years saw research – we had to produce ‘evidence of need’ in the language of NHS officials – and a lot of groundwork before eventually we were able to write a detailed bid for a community ME service. Once the bid was approved and OCCMET (Oxfordshire CFS/ME Community Team) was set up we were involved with recruitment, selection and training of staff. We aimed all along to build up working relationships with people who make decisions in the PCT and with clinicians. The frequent re-organisations of the NHS and hence PCT personnel make this work very frustrating at times.

Though the initial idea was for a clinic the remit is now far wider. The Clinic Group meet about every two months and keep a watching brief on OCCMET and other services treating ME. We also represent patients at the three-monthly Advisory Group meetings (advising NHS staff and managers about ME services); we have frequent liaison links with individual members of the Team. We also have links with other local national and international ME Groups; we try and keep up to date with latest research developments. We are also concerned with strategy for the future of ME services throughout the county, for all ages and all levels of severity; we continue to campaign to make ME services as good as possible. We can raise general concerns about the service although we cannot take up individual cases.

OCCMET is one of the best services in the country and unlike many others OCCMET makes home visits and is not psychologically based; these are two features we have always stressed. It also exceeds its targets on waiting times and home visits. Of course we are continually trying to make a good service even better; at the same time we have to be realistic about NHS financial and staffing limitations and the well known targets set by central government. There are possibilities for future development and we are making sure we are fully involved at all stages.

As you know, the current campaign concerns children with ME. Of course education is a very large part of their lives so we are building on our sympathetic contacts in the education world and so as to improve things for our young people.

All but one of us (a carer) are ill with ME and have to try and manage the considerable work for OMEGA with our health limitations. It is very rewarding to feel useful and know that the work makes a difference. If you would like to be involved please get in touch at the newsletter email address.  
Jan and Patricia on behalf of the Clinic Group

## **Subscriptions for 2009**

Helen Garfitt has now agreed to look after our subscription income. So if you haven't yet paid your subs for this year, please send your form and cheque to Helen at:

Birdsay, Latchford Lane, Great Haseley, Oxon OX44 7LA.

The sub is £10 (waged) or £5 (unwaged). If you can make a donation, that is very helpful. We understand that many people are not employed; if you have real difficulty in paying, do give our Membership Secretary Lesh a ring.

For email reminders of meetings, just include your email address.

## **Complaints and feedback about NHS treatment**

Sometimes members tell us about difficulties they have had with the NHS. OMEGA i.e. the Clinic Group, would like to know about your experiences of ME treatment and we can feed back appreciation and general concerns. However, we cannot take up individual cases; but there are people who can help.

The procedure is to first take the matter up with the individual member of staff concerned. Most difficulties can be resolved in this way. If you do not get a satisfactory response then take the matter up with the PCT (Primary Care Trust) or relevant Hospital Trust or with PALS (Patient Advisory and Liaison Service) who offer a free confidential service for patients, carers and relatives. They offer advice and information about the NHS and related services and can help when you have a concern or don't know where to turn.

PALS phone number is 0800.052.6088 email [pals@oxfordshirepct.nhs.uk](mailto:pals@oxfordshirepct.nhs.uk)

## **GETTING TO KNOW YOU**

Our column this time features our volunteer helpers from Oxford Brookes. We couldn't bring you their pictures but will hope to put them in next time. Mary and Kim were good enough to answer OMEGA's questions:

**Mary Horan**

**Job role for OMEGA  
Administration**

**Area of Oxfordshire/Oxford you live**

Barton

**Who you live with (including pets)**

I moved to Oxford from Glasgow in January. Living on my own, but my partner (currently based in Glasgow) has just been offered a job in Oxfordshire so will be moving down here soon!

## **What is your Main Job (not OMEGA)**

Sustainable Travel Co-ordinator at Oxford Brookes University

### **1. What are you enjoying about your work for OMEGA?**

I have enjoyed finding out more about ME and how it can affect people; it was particularly interesting hearing the stories from the people who volunteered to be "The Faces of ME" on the poster. I have also enjoyed meeting new people.

**2. What was the most interesting or surprising thing you have learned about ME?** I didn't know that the symptoms of ME can include headache/migraine and muscle pain. I had no idea that the symptoms were so wide-ranging.

**3. Tell us something that you've done recently that you've enjoyed?** I was in Glasgow last weekend and managed to catch up with 10 people (11 people if you include my friend's bump who is eight months pregnant!) who I haven't seen in a while which was great!

**4. What gives you joy?** Food and drink is one of my passions – I love going to a restaurant with excellent food and service and taking my time over my meal and enjoying the company of whoever I'm with.

## **Kim Francis**

## **Job Role for OMEGA Web Developer**

### **Area of Oxfordshire/Oxford you live**

Risinghurst, Oxford

### **Who you live with (including pets)**

Live with my husband Andrew, son Jamie & daughter Ingrid (when not at Uni). Have an adopted stray cat called Munchkins.

### **What is your main job?**

I work at Oxford Brookes University, till recently a Project manager/web designer for two projects, and soon a full time role supporting and managing the students on-line programme.

**1. What are you enjoying about your work for OMEGA?** - Like meeting everyone. Excited about getting a website running to help more ME sufferers and carers get together and get into OMEGA.

**2. What was the most interesting or surprising thing you have learned about ME?**- quite shocked about HOW exhausted everyone gets and didn't realised how much the eyesight is affected.

**3. Tell us something that you've done recently that you've enjoyed?**  
Like knitting and gardening and crafty things

**4. What gives you joy?** Paddling in the sea, knitting and trying to design something knitted, chilling out in the garden.

**OMEGA PICNIC Saturday 8<sup>th</sup> August Florence Park, off Cowley Rd., Oxford;** turn into Littlehay Road (near the Q8 Garage) then first right into Rymers Lane. Go to the last gate into the park (opposite the allotments). You can able to see the bandstand from there. There is space to park in the road.

**Oxfordshire ME Group for Action (OMEGA).** General Enquiries to Lesh Lender at: 4 Bursill Close, Oxford OX3 8EW, Tel. 01865 766310, E-mail: [leshl@talktalk.net](mailto:leshl@talktalk.net)

**Meditation Group:** meets Monday August 3 11am - 3pm. (please ring or email Jan for details) then monthly last Friday of the month 11am - 1pm. Details of all meetings from [omega.meditation@phonecoop.coop](mailto:omega.meditation@phonecoop.coop) or ring Jan on 01865.718274

**S Oxon Social, Waterfront Café, Benson.** Monday, 14<sup>th</sup> September 12midday to 2pm . (Ring Tessa Keys 01491 838727 for details.) On Oxford to Reading bus route. All welcome.

**Oxford area Social gathering.** Four Pillars Hotel, Sandford-on-Thames, FIRST MONDAY of EVERY MONTH. (Second Monday of the month if it is a bank holiday.) On bus route from Oxford. Phone Diane Drayson on 01235 520104 or Lesh Lender on 01865 766310.

**Wantage and Grove ME/CFS Support Group, WAGS,** meet at the Cornerstone Coffee Shop in Grove. Contact Dorothy Hillbeck at 01235 765329 for dates and times

#### **OMEGA Volunteers**

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Action for ME support line (open to all): Monday to Friday 11 am to 1 pm 0845 1232314, and also 6.30 to 8.30 pm Mondays (except Bank Holidays).		

OMEGA Newsletter production team: Cathy Brocklehurst, Lesh Lender, Jan Seed, Patricia Wells. Next copy deadline is 31<sup>st</sup> August 2009. To receive your newsletter by email, please write to: [newsletter.OMEGA@googlemail.com](mailto:newsletter.OMEGA@googlemail.com) with 'email newsletter request' in the subject line.

Contacting OCCMET: **New number: 01295 819191**, or e-mail to:  
[occmet.administrator@oxfordshirepct.nhs.uk](mailto:occmet.administrator@oxfordshirepct.nhs.uk)



