



# Omega Newsletter

Volume 72

Winter 2011



Oxford as a  
winter  
wonderland,  
on the day  
of the  
OMEGA  
Christmas  
lunch

Welcome to our first edition of the newsletter for 2011! This edition contains some more of Jo Breheny's ME friendly activities in Oxford (page 2), some photographs and details about the OMEGA Christmas lunch (page 3), feedback from the Volunteer Fair (page 8), a report from the Clinic Group from Patricia Wells (pages 5-6), a letter to the Oxford Mail by Jill East (page 4) and Norman Booth's proposal for a Biobank for ME (page 8). There is also particularly useful information on changes to benefits by Jan Seed (page 10), advice on getting the help you need by Cathy Brocklehurst (pages 11-13) and details on the Neurological Alliance by Norman Booth (page 9).

Happy reading!

## Mindfulness Meditation Drop-in Group 2011

*"Your deepest presence is in every small contracting and expanding." Rumi*

For people experiencing chronic pain, acute pain and other forms of suffering. The evenings will comprise led meditations (including occasional movement meditation) with an opportunity to ask questions and share experiences. The intention behind the meditations will be on cultivating kindness towards ourselves and developing awareness and acceptance of the present moment.

Thursday evenings 6.30 to 8.00pm: 13th January, 10th February, 10th March,  
68 Lytton Road, Cowley, Oxford OX4 3NZ. Suggested donations between £8 and £12. Bring blankets/ mats/cushions as needed. Wear loose warm clothing.

Further details: Marguerite Wallis (Breathworks Trainer & physiotherapist with 30 years of meditation experience): 01865 718240; margueritewallis@phoncoop.coop

Please note that this is separate from the monthly OMEGA meditation group which is open to all (see diary for details).

# ME friendly things to do in Oxford

## Meditation:

Cost: Varied

There are regular monthly OMEGA meditation sessions (see diary pages for details). These are specifically tailored for people with ME. Some of the group join in by phone or by Skype, or just meditate at the same time at home, if they are unable to join in person. Anyone is welcome to attend, in person or virtually. There is also a monthly mindfulness meditation for chronic pain and illness group which meets monthly. Contact Marguerite Wallis 01865 718240; margueritewallis@phonecoop.coop. There are weekly meditation classes held in the centre of Oxford: fiamma@talktalk.net. You can download a mindfulness bell to remind you to pause and breathe - free and simple to download: [www.mindfulnessdc.org/mindfulclock.html](http://www.mindfulnessdc.org/mindfulclock.html)

Meditation practice comes with a myriad of well publicised health benefits including increased concentration, decreased anxiety and a general feeling of happiness. It can take many forms including just a 5 or 10 minute daily meditation.

There are also CDs, books, tapes, pod-casts, videos, online tutorials on You-tube and if you type the subject into your browser. Also there are many meditation days and classes available in the area to be found online, in newspapers and shop windows.

## Virtual holidays:

This is a brilliant idea, by Zoe (Williams).

To take a virtual holiday:

- (A) Decide where you are going
- (B) Gather books on and pictures of the place you are visiting
- (C) Have (as much as possible) food from or inspired by the destination
- (D) Listen to music from there.
- (E) Watch a film, filmed in the area.
- (F) E-mail friends/family from your "holiday" telling them what it is like.

## Birdwatching:

This can be accomplished from home if you have a garden or even somewhere to put a bird feeder. Books and DVDs on native birds can be obtained from the library or bought, or you will find information online. You may also wish to buy or borrow binoculars.

It is also possible to observe wildlife through the window whilst lying in bed, on the floor or on the sofa, depending on where you live.

By Jo Breheny

## OMEGA Christmas Lunch 2010

Twenty-three souls braved the chilly December weather to attend our annual Christmas Lunch at Brookes Restaurant in Headington. The food was good festive fare and the company was great. Crackers were pulled, hats worn and bad jokes told. We were seated at two long tables but moved around a bit so we could talk to as many people as possible. Of course we remembered all our members who were not well enough to be with us. Hopefully we can see as many of you as possible next December.

David Polgreen



The OMEGA Christmas lunch 2010. As usual a great turn out, and a lovely occasion. We've chosen the photo where everyone is looking up and smiling - there's rather a lot where people are leaning on the table looking tired, but we see enough of that every day!



The turkey option at the lunch – black and white doesn't do it justice!

A letter to the Editor of the Oxford Mail

*Twenty-plus years ago, as a newly afflicted person with ME, I was enabled by my GP to attend a research project in Liverpool, with a view to taking part. I spent an arduous day reaching the clinic, was given some tests and chats and left with a photocopied leaflet advocating graded exercise therapy. Since I had prescribed that for myself and found it to be a recipe for disaster, I threw the leaflet away. (And, after a week, was recovered from the devastating journey.)*

*Roll on to last year. My kind GP in Banbury suggested I join Churchill's ME research programme. Imagine my amazement when I found an entire set of duplicate circumstances. They are still asking ME patients to travel long distances while they arrange languid interviews at their clinics. They are still advocating GET despite massive doubts hovering over the whole idea, both from patients and from medical research. There are just two little differences. One is that they have added cognitive behaviour therapy, but not as an extra idea, rather as an alternative which they can ask you to take instead. And the leaflet is now printed.*

*At the cost of over a thousand pounds I have attended a private clinic in London. There the approach is entirely eclectic, they consider ME has many causes, many manifestations and needs many varying treatments. It is in sharp contrast to the laidback, know-all attitude of the NHS. I am finding it beneficial, although it is early days.*

*WHAT are the NHS doing? Millions of pounds have supported these so-called 'research projects' (no research here! they know the answers). This is money which could have been spent elsewhere in the NHS, areas where it is sorely needed, like home care for the elderly.*

*Do you suffer from ME? If you agree with me - or even if you don't - please see your MP and ask for his or her support. Tony Baldry is MP for Banbury and is making enquiries. At the very least, the absurdity of making ME patients take long journeys, dosing themselves with caffeine etc. to keep going is obvious. How often are you feeling too unwell to venture out? That is when someone should be coming to see YOU. They should do genuine research and look into the characteristics of the sick patient.*

*Sincerely, Jill East.*

## Report from the Clinic Group January 2011.

We said we would try to report to you from time to time about what the Clinic Group (OMEGA's campaigning arm) is doing. One of our main tasks is to keep in regular touch with the OCCMET team who continue to do great work.

As individuals, and even as a small group we have quite an impact, but we can only do so much. We are always looking for others who may want to contribute to the campaigning, even in a very small way - it all adds up. We have a lot of fun and it's very satisfying working together. In addition, joining forces with other groups and organisations lends strength to our voice and this is what we have done as you see below. Norman maintains our invaluable national and international contacts and keeps us up to date on research and his important contribution to this.

Norman is also our link with WMMEG (West Midlands ME Groups Consortium) which, as the name suggests, is the voice of many other groups. One key achievement this year is that we have joined the Oxfordshire Neurological Alliance where Norman and Cathy represent our interests. As we know CFS/ME is recognised by the WHO as a neurological illness.

Until recently it has been hard to get this classification accepted locally. However last year the PCT (Primary Care Trust) commissioned a report on the needs of people with long term neurological illnesses. We happened to see a draft; the good news was that CFS/ME was listed among the other illnesses; the bad news was that the entry was poorly researched and contained many errors. We worked hard to re-write it and about one-half of our amendments are included in the final version. We have put a link to this on the website.

OMEGA has also been represented at a group set up by the PCT to devise and implement a 'patient pathway' through the

options for treatment on the NHS. (OMEGA wrote a proposal for such a 'pathway' in 2004; what we didn't know was the amount of bureaucracy and agreements required for it to actually work.)

We were consulted about the long awaited Information Notes and Referral Information for GPs. This is now going through the bureaucratic processes of NHS committees and IT advisers, so that GPs have easy access to it. We believe that when eventually they are available to GPs it will make a difference to the treatment we get. One very important achievement was to get agreement for all parts of the service to use common diagnostic criteria. Advances in understanding of the illness over the past 20 years means there are now more tightly defined criteria for diagnosis.

We do feel frustrated at times. Despite central government rhetoric about 'patient involvement' (and even 'a patient led health service') and, locally, agreements at meetings to consult us, this doesn't always happen. Our suggestions are not always accepted. It is not part of the culture of the NHS to talk to us in this way, so we often have to ask, or happen to hear of things going on and then we intervene. The NHS is a very big bureaucracy. There is much individual good-will but this can get lost in the structures (governance rules, targets etc) of such a complex organisation.

You may know that the Barnes Unit is now called the Health Psychology Service, and the group of clinicians working at the JR Hospital are called 'ORH Fatigue Service'. We stumbled across one of their documents on the net recently. It was the Patient Information Leaflet put out by the 'ORH Fatigue Service' which we found at <http://www.oxfordradcliffe.nhs.uk/forpatients/090427patientinfoleaflets/101109chronicfatigue.pdf> We thought it possibly misleading and have highlighted some changes.

We have consulted Oxfordshire LINK (Local Involvement Network) which has now replaced other consultative arrangements (e.g. Community Health Councils). LINK exists to implement NHS policy to consult patients – more on their website [www.oxfordshirelink.org.uk](http://www.oxfordshirelink.org.uk). We learned that our rather frustrating experience is common to many patient groups.

However, all the services recognise our presence. OMEGA appears as a resource on their patient leaflets, and we have achieved a great deal in the ten years we have been campaigning. We continue to say what patients want and we will continue to say what people with ME and their carers want and need.

We are concerned, as most people seem to be, about the White Paper published on 12.7.10. It proposes to dissolve the PCTs and replace them with GP Consortia, so that GPs will have a more direct role in commissioning (deciding what treatments to offer patients and paying for services). We sigh with frustration. We smile with nostalgia about this last of many (five at least) reorganisations we have witnessed. More worryingly, some of us believe the

White Paper will promote privatisation and competition – when we have been working so hard to promote co-operation between parts of the service. We think our best way forward is to ensure that as many clinicians (doctors and other health care professionals) and managers know about CFS/ME and what patients need. We shall, to the best of our ability, keep voicing the needs of patients to whoever is making decisions about treatment.

Is this the kind of thing you would like to be involved in? - improving treatment for people with ME? If you are not well enough yourself, is there anyone who could represent your interests and the interests of other people with ME and their carers? We are especially appealing to carers, partners and friends; plus those people with ME well enough to attend the occasional meeting, or read through some documents. Please give any of us a ring or email [newsletter.OMEGA@googlemail.com](mailto:newsletter.OMEGA@googlemail.com) with Clinic Group in the subject line, or phone 01865 766310.

PMW et al 9.1.11

## **Oxfordshire Unlimited**

Oxfordshire Unlimited (OU) is a new organisation campaigning for the rights of disabled people in Oxfordshire. They have already achieved some successes in their equality campaigns including working for accessible transport and seats for shoppers. They are currently campaigning about abuse of Blue Badge Parking Spaces. If you ever see a Blue Badge space being used by a vehicle not displaying a badge, you can ring them on 0845 121 4112. OMEGA has joined OU. If you would also like to join as an individual, contact : [sally.latham@oxfordshire.gov.uk](mailto:sally.latham@oxfordshire.gov.uk) or ring 01869 244374 (email preferred).



## Making light of the funding cuts!

Adrian Lauder from Oban submitted this note to Action for M.E. about proposed cuts to the National Health Service. Please do not read if you are offended by rude humour.

The British Medical Association has weighed in on the new Prime Minister David Cameron's health care proposals.

The Allergists voted to scratch it, but the Dermatologists advised not to make any rash moves.

The Gastroenterologists had a sort of a gut feeling about it, but the Neurologists thought the Administration had a lot of nerve.

The Obstetricians felt they were all labouring under a misconception, while Ophthalmologists considered the idea short-sighted.

Pathologists yelled, "Over my dead body!" while the Paediatricians said, "Oh, grow up!"

The Psychiatrists thought the whole idea was madness while the Radiologists could see right through it.

The Surgeons were fed up with the cuts and decided to wash their hands of the whole thing.

The ENT specialists wouldn't hear of it.

The Internists thought it was a bitter pill to swallow, and the Plastic Surgeons said, "This puts a whole new face on the matter."

The Podiatrists thought it was a step forward, but the Urologists were pissed off at the whole idea.

The Anaesthetists thought the whole idea was a gas, and the Cardiologists didn't have the heart to say no.

In the end, the Proctologists won out, leaving the entire decision up to the a\*\*\*\*\*s in London.



### New Year's Resolutions (from Action for M.E.)

As we move forward into 2011, we plan to focus on:

- setting up the UK's first biobank for M.E. research;
- launching our new website at [www.actionforme.org.uk](http://www.actionforme.org.uk)
- campaigning for an exemption from the Work Capability Assessment for people diagnosed with moderate to severe M.E.
- the reform of Disability Living Allowance
- representing the views of people with M.E. on GET, the PACE trial and the NICE review
- opposing the one year time limit on contribution-based Employment and Support Allowance
- telling decision makers how proposed Housing Benefit changes will affect people with M.E.
- defending social care for the severely affected.

Have we missed anything out? Tell Policy Officer Tris  
([tristana.rodriquez@afme.org.uk](mailto:tristana.rodriquez@afme.org.uk))

## Proposal for a UK Biobank for ME

Over the years more than one OMEGA member or ME sufferer has spoken to me about donating their body (after death) for biomedical research. Because people with ME are now barred from giving blood, it may be more likely that they will be willing to donate organs for ME research. The national charities (the ME Association and Action for ME) have been interested in the possibility of a post-mortem Biobank for some time, but only in recent months has the idea really gathered momentum. This is due largely to a study involving Dr Derek Pheby, leader of the CFS/ME Observatory project, and Drs Eliana Lacerda and Luis Nacul of the London School of Hygiene & Tropical Medicine. The results show wide interest and illustrate the benefits of serious dialogue between scientists and sufferers. It is estimated that a Biobank would cost £200,000 to establish and be used for research projects for the first 18 months.



Major donations for the ME Tissue Bank Project can be sent to the London School of Hygiene & Tropical Medicine, London WC1E 7HT (tel. 020 7958 8134) and smaller individual donations can be made via Action for ME by telephoning 0117 930 7293 or by post to FREEPOST RSAC-SGCT-ZREY, Action for ME, PO Box 2778, Bristol BS1 9DJ.

Norman Booth

## Volunteer Fair 2010



Omega had a stand at the Volunteer Fair which was held on 14<sup>th</sup> October 2010 at Oxford Brookes University.

Jo Breheny (pictured, left) helped to organise OMEGA's stand and would like to say a big thank you to everyone who was involved and helped out.

Jo really appreciates the time people gave and the effort everyone made and the support that she was given. The day was a great success: as well as generating lots of interest from potential volunteers, OMEGA also recruited a new member.

OMEGA now has several new volunteers working with us: Clea Desebrock, who will be doing some marketing work, two book-keeping volunteers from Brookes, studying Accounting & Finance, through a scheme with OCVA (Oxford Community and Volunteer Action). Trace-Leigh Johnston and Lutfiye Coban will be helping Helen Garfitt (our treasurer) with our accounts for a short project. A very warm welcome to them.



## Oxfordshire Neurological Alliance

The Neurological Alliance is a national collaborative forum covering a spectrum of neurological illnesses, including Myalgic Encephalomyelitis. The Oxfordshire branch, the Oxfordshire Neurological Alliance (ONA), was launched in March 2009 at a well attended meeting which included representatives from the Oxfordshire PCT and Oxfordshire Social Services. Baroness Professor Susan Greenfield gave a keynote speech “The Brain in Health & Disease”. OMEGA became a group member in order to represent patients with ME, with Cathy Brocklehurst as our official representative. The ONA is recognised and listened to by Oxfordshire PCT because it acts as the patient representation for the PCT’s Neurological Conditions Implementation Group.

“ **Have your say!** ”

What are the Health and Social Care issues that are important to you?

How can we work together to improve these services?

Your chance to help the Oxford Neurological Alliance to agree its priorities.

A workshop facilitated by Jeremy Spafford at  
Headway Oxford, 4 Bagley Wood Road, Kennington, Oxford, OX1 5PL  
4 – 7.30pm, Monday 31st January

Light refreshments provided

Please let us know if you can come.  
Contact: Dennis Morgan  
Chairman – Oxford Neurological Alliance  
dmorgan@mssociety.org.uk  
020-8438-0841

**OXFORDSHIRE**  
**Neurological Alliance**

Oxford Neurological Alliance, Bourton House, 18 Thorney Leys, Witney, Oxfordshire, OX28 4GE

Supporting people affected by a neurological condition

The ONA has a small committee that meets regularly and has plans for four open meetings during 2011. The first is a workshop on **Monday 31<sup>st</sup> January 4.00pm to 7.30pm** where people affected by a neurological condition can **have their say** and help the ONA to find answers to the questions:  
What are the Health and the Social Care issues that are important to you?

How can we work together to improve these services?

What should ONA’s priorities be?

For more details, contact:

Dennis Morgan  
Chairman – Oxfordshire  
Neurological Alliance  
[dmorgan@mssociety.org.uk](mailto:dmorgan@mssociety.org.uk)  
020 8438 0841

Further dates for your diary are the second open meeting – Tuesday 29<sup>th</sup> March is the AGM with a guest speaker, and the third on Wednesday 29<sup>th</sup> June with talks on Health Reforms and the new GP consortia being established to largely replace the PCTs. (See also the report from the Clinic Group above.)

Norman Booth

## **Benefit Changes**

Jan Seed

As many of you will know, the benefit system changed in October, and the Incapacity Benefit (IB) was replaced by the Employment Support Allowance (ESA). To obtain this benefit (including if you are currently on IB), you have to have a Work Capability Assessment (WCA). This assessment has been much criticised by Disability groups, including the national ME Charities; and there is to be a review of this benefit and the way entitlement is decided. For example, the ME Association ([www.meassociation.org.uk/?p=1639](http://www.meassociation.org.uk/?p=1639)) has submitted a comprehensive document to the review, outlining the many problems that people with ME will face.

Those of us who have applied for benefits know that the forms are difficult, and exhausting to fill in. The questions are often irrelevant and people with ME often have to go to appeal to explain the reality of the illness (where often they succeed). The new benefits assessments seem to be worse. The MEA says that about 75% of people are refused the ESA (maybe much more for people with ME), 14% placed in the "work-related activity group" (where they are expected to be in employment within one year), and only 6% are in the "support group" classified as unfit for work, where no improvement is expected. Many people with ME would see themselves as belonging to neither group. Some people with ME may get well enough to work, but this is not at all likely to happen within one year! What is likely is that people will simply be transferred to unemployment benefit and subject to the pressure to find work. This is more likely to be detrimental to their health.

The key points that the MEA raise are:

- variability of ME/CFS symptoms (ignored on the WCA)
- inability to sustain physical and mental performance for more than a short period of time – even though a person with ME/CFS may be able to carry out the specific tasks involved in a WCA assessment on a one-off basis.
- a points scoring system that fails to take account of key ME/CFS symptoms such as fatigue and pain
- a points scoring system that fails to ask appropriate employment-related questions where they do partially relate to ME/CFS
- a points scoring system that concentrates on household tasks rather than work-related tasks and fails to take any note of the type of employment that the claimant normally undertakes
- a failure to take note of, or even not believe, what people with ME/CFS are reporting in both written submissions and when they are being assessed or examined by health professionals employed by ATOS.

There are many other proposed changes and cuts in benefits for carers, and for Disability Living Allowance (DLA). At the present time we are not sure exactly what these will be. However, if you feel that you would like the assessment of benefits to take into account the needs of people with ME and their carers, why don't you write a short letter or postcard to your MP? Let us know at [newsletter.omega@googlemail.com](mailto:newsletter.omega@googlemail.com) if you've written - and if you get a reply! Also let us know what your experience has been with the WCA.

## Getting the help you need

Often when you are ill, friends and family will step in to ensure you are looked after. However, some people find themselves in a position where they need help with day to day living, and for a long period of time. People's needs vary considerably and you may need help with washing and dressing or when pain or fatigue is at its worst. Some people need help with meal preparation, others with housework, shopping and gardening. Or you may need help to access social activities or to get out of the house.

Unless you are so ill that you qualify for a direct payment from social services, you generally have to pay for help, although there are certain benefits you may be able to claim, such as Disability Living Allowance or Attendance Allowance (if you are 65 or over) which can help with some of the cost. Likewise someone caring for you may be able to claim Carer's Allowance. You can find out more about these benefits on websites such [www.direct.gov.uk](http://www.direct.gov.uk), by visiting an advice agency such as Citizens Advice or by using the Benefits in Practice service at your doctor's surgery, if your surgery is a member of the scheme.

If you find yourself in a position where you need help with day to day living, there are several ways you can access some help:

- approaching a care agency
- using social services (there may be eligibility criteria)
- employing your own carer or PA (Personal Assistant)
- using a volunteer
- using a service such as Homeshare

### Care Agencies

Getting help from a care agency is relatively straightforward. You may know of a particular care agency, or you can find a list in any telephone directory. The Access Team for Social Services, on 08450 507 666 also have a list they can send you. If you prefer to use the internet, the Care Quality Commission's website, [www.cqc.org.uk](http://www.cqc.org.uk), has a directory function which lists all the care agencies in your area if you put in your postcode.

Whatever care agency you choose, the approach is pretty much the same - after an initial chat on the phone, they will arrange a visit where their care manager visits you at home to assess your care needs, and draws up a care plan and carries out a risk assessment. You can expect to pay from £14 an hour for help and slightly more for weekends, bank holidays and any anti-social hours (defined by one agency to be between 7pm and 10pm at night). You can book shorter slots than this. Some agencies offer a sleep-in service where a carer stays overnight for around £70 a night. Very few care agencies seem to offer visits after 10pm at night.

It's probably worth working out in advance how often you need help in a week and what form that help will take.

### Social Services

Approaching Social Services is also straightforward. For Oxfordshire, the main contact number for the Access Team is 08450 507 666 and you can have an initial chat to them about your circumstances. If you prefer you can do an initial enquiry online and fill out a background information form and someone from the Access Team will contact you. The form covers areas such as personal information, your problems, their impact on your life and what you think may help. To use the form, go to the [www.oxfordshire.gov.uk](http://www.oxfordshire.gov.uk) website, look at the 'Council services' section, at the bottom of the main page and click on 'Health and social care', and you can request a needs assessment online.

It's always worth approaching the Access Team and discussing your situation with them and they will let you know if you're eligible for direct payments. However, not everyone is eligible - and only people with a 'substantial' or 'critical' need will qualify. These are defined on the [www.oxfordshire.gov.uk](http://www.oxfordshire.gov.uk) website and can be found by clicking on 'Health and social care' which is in the 'Council services' section, at the bottom of the main page. Then click on 'Getting care' then 'Fair access to care' and you can read more. You also have to pass

a means test, with the threshold of income / savings currently standing at £23,250.

However, Social Services can still advise you and guide you even if you're not eligible and they may come up with solutions even when you believe your situation is hopeless.

After the initial contact by phone or by filling in the background information form, a social worker or care manager will visit you at home and do a formal assessment. If they feel you need the help of an occupational therapist, then a functional assessment will also be arranged. The person I spoke to at Social Services says you can have any equipment the occupational therapist recommends on loan.

The variability of ME can lead to the needs of people with ME being under-estimated, especially as people tend to be seen when at their most well and active. Useful information to have before you talk to them might be how many periods of fatigue you have in a typical week, how long they last and how incapacitated you are during them. If you are totally incapacitated or totally housebound or likely to become so, then say so!

If you have a child who suffers from ME, then Social Services do take initial enquiries for children (under 18s) and these get passed onto their Children and Family Teams.

Following an assessment, if you are eligible for help then either:-

1. You will be offered money in the form of a 'personal budget' to buy the care services you feel would best meet your needs and improve your situation. OR
2. You may prefer that the council organises and pays for care services on your behalf and your budget is held by the council as a 'virtual budget' and they will put in place the services you need. OR
3. You may wish to choose care services outside of the council's internal support and your budget will be paid to you directly via a 'Direct Payment' into either your own bank account or to a suitable organisation who will manage your direct payment for you.

You will also be offered the help of a Support Broker who can assist you with looking at all your options for support and who will help with pulling your Support Plan together.

### Support Brokers

If you are choosing care services outside of the council, you will probably need the services of a broker. They can provide recommendations and suggestions for putting your care plan into action. There are two organisations in Oxfordshire, Oxfordshire Care and Support Options (01235 849405) and Advance (01235 817960) who provide support brokerage services. If you do not qualify for Direct Payments you can still use the services of a broker to help arrange care but there may be a charge for their help.

### Care Plans

One useful website is [www.takingcontroloxon.org.uk](http://www.takingcontroloxon.org.uk). It has some examples of care plans and lots of information about self directed support.

### Employing someone

Employing your own carer or PA can give you greater control over the process. You can see a list of approved Personal Assistants on [www.takingcontroloxon.org.uk](http://www.takingcontroloxon.org.uk) by clicking on 'I want to get in touch with an Approved Personal Assistant'.

There are a number of issues to consider when employing a Personal Assistant, such as tax, national insurance, holidays and redundancy, but there are organisations who will help with things such as payroll. There is also a very helpful booklet on [takingcontroloxon.org.uk](http://takingcontroloxon.org.uk), in the 'I use social care services' section. If you look at the page 'Hiring a Personal Assistant' you can download the booklet, 'Employing your own PA'.

### Homeshare

If you are willing to share your home, Homeshare aims to match you with a person who needs accommodation who is also willing to give support with items such as shopping, light housework and gardening for

10 hours a week in exchange for living rent-free. Personal care (washing and dressing and suchlike) isn't included in the scheme but help with other tasks is. You may also benefit from the presence of another person and the companionship that they provide. Everyone, homesharers and householders, is interviewed by the Homeshare Coordinator and references are taken up. In addition, homesharers undergo a police check. There is also a written agreement drawn up and regular support and review by the Coordinator. Homeshare Oxford is on 01865 894956.

### **Registering for Emergency Care**

If you are being cared for by an unpaid carer, your carer can register for emergency care with A4e. If an emergency arises and they cannot care for you, for 48 hours A4e will send a carer to take over free of charge. If, for any reason, your emergency lasts for more than 48 hours, they will flag up to social services that you need help. You need to register in advance for this scheme and fill out a comprehensive registration form so that the replacement carer knows what to do. You will be given a registration number, which you quote if you need an emergency carer. A4e are on 01865 374430.

### **Carer's Assessments**

A carer has the right to ask for an assessment from Social Services. It's also worth telling your GP you are a carer.

### **Voluntary organisations**

Sometimes you need help with errands or getting to a doctor's or hospital appointment

and various parts of the county run good neighbour schemes.

One example is the neighbourly help scheme based at NOA, the North Oxfordshire Association in Summertown. It covers the North Oxford area and to request help you need to ring 01865 552295 a day or two before help is needed. They will see if they have a volunteer who can help. One of our members has used a volunteer from this scheme to visit the library on her behalf.

Oxfordshire County Council has a list of some of these schemes and you can contact Barbara Jordan on 01844 217904 for a copy.

You may find the church is a possible source of help and your minister may know of people wanting to be helpful.

Sometimes the need for care is so that you can maintain a social life during your illness but you need extra support in order to access social activities. Ryder Cheshire run a service in most parts of the county using volunteers – so if you have a particular interest – you can have a volunteer to help take part in an activity each week. Contact 01926 485446 for details.

Finally, for older people, Age UK operate a Phone Link service. This is usually for people over 55 although they will consider a request from a younger person. This helps with the isolation that ME sufferers sometimes experience. A volunteer will phone you once a week and see how you are. They may discuss day to day things with you or they may identify areas where you need further help and support. For details about the service contact Age UK on 01235 849400.

Cathy Brocklehurst

## Diary Dates

### OMEGA Meditation

28 January, 25 February and 25 March, all at 11am-1pm  
[omega.meditation@phonecoop.coop](mailto:omega.meditation@phonecoop.coop) or ring Jan Seed on 01865-718274

S Oxon Social Group, Shillingford Bridge Hotel, Monday 14th February, 12 midday to 2pm. Ring Tessa Keys on 01491 838727

**5 March 12.00 to 2.00pm** CommitteePlus Like what OMEGA does? Have ideas about what we could do? Help already in any way? Join the committee over a bring-and-share lunch, preferably vegetarian, at the Upper Room, Seacourt Hall (behind the Elms Parade Shops, opposite the Co-op in Botley) between 12.00midday and 2.00p.m. We'll have a nice social time and share ideas about the future of OMEGA. Ring Lesh on 766310.

9 April **AGM** 2.00pm - 4.00pm Ridgefield Community Centre East Oxford  
 Speaker – Phillippa Sharpe (Assistive Technology Occupational Therapist)

**FIRST MONDAY of EVERY MONTH** (EXCEPT in March) **Oxford area Social gathering.** Four Pillars Hotel, Sandford-on-Thames. (Second Monday of the month if it is a bank holiday.) On bus route from Oxford. Phone Jo and John 01993 866610 or Lesh Lender on 01865 766310.

**Book club:** Group in Bicester is flourishing, Ring Nicky Williams for next meeting and special library membership package 07813 942474.

**Parent Support Group:** Contact Anna Russell Pritchard about the new group. 07825 886 331 or [anna.russell.pritchard@uwclub.net](mailto:anna.russell.pritchard@uwclub.net)

Monday 31<sup>st</sup> January 4.00pm to 7.30pm

"Have your say!" – your chance to help the Oxfordshire Neurological Alliance to agree its priorities. Workshop at Headway Oxford, 4 Bagley Wood Road, Kennington, Oxford OX1 5PL. (This is directly across The Avenue, Kennington Road from St Swithun's C of E on the no. 35 bus route). Light refreshments will be provided. Please contact Dennis Morgan, Chair of ONA ([dmorgan@mssociety.org.uk](mailto:dmorgan@mssociety.org.uk) or telephone 020-8438-0841), if you would like to attend.

## Contact Information

Oxfordshire ME Group for Action (OMEGA). General Enquiries to Lesh Lender at: 4 Bursill Close, Oxford, OX3 8EW. Tel. 01865 766310, E-mail: [ltrl3@tiscali.co.uk](mailto:ltrl3@tiscali.co.uk)

OMEGA Website: [www.ocva.org.uk/omega](http://www.ocva.org.uk/omega)

### WANTAGE AND GROVE ME/CFS SUPPORT GROUP, WAGS,

Cornerstone Coffee Shop, Grove. Contact Annie Kingsbury for dates and times.

**OCCMET: 01295 819191**, or e-mail:

[occmnet.administrator@oxfordshirepct.nhs.uk](mailto:occmnet.administrator@oxfordshirepct.nhs.uk)

Chairperson	Patricia Wells	01865 554648
Treasurer	Helen Garfitt	01844 298619
Meditation Group	Jan Seed	01865 718274
Membership Secretary	Lesh Lender	01865 766310
Publicity		
Wantage contact	Annie Kingsbury	01235 763813
Clinic Group contact and OMEGA rep. for OCCMET	Norman Booth	01235 833486
Banbury contact	Jill East	01295 271366
Bicester contact	Nicola Williams	07813 942474
Witney and 'Invest in ME' contact	Flora McKenzie	01993 774834
South Oxfordshire ME/CFS Support Group	Tessa Keys	01491 838727
<i>Action for ME support line (open to all): Monday to Friday 11am-1pm 0845 1232314, and also 6.30-8.30pm Mondays (except Bank Holidays)</i>		

OMEGA Newsletter Editor for this issue Mary Horan. Production team: Cathy Brocklehurst, Lesh Lender, Jo Breheny, Jan Seed, Patricia Wells. Email address [newsletter.OMEGA@googlemail.com](mailto:newsletter.OMEGA@googlemail.com) To receive your newsletter by email put 'email newsletter request' in the subject line. Send articles, jokes, cartoons or letters for publication with 'Editor' in subject line.