



Omega Newsletter

Volume 68

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Whatever gets you through

We are very excited to announce the launch of our new website. www.oxnet.org.uk/omega More details on p11. Huge thanks to Jan and our volunteer helper Kim who have worked very hard to make this possible. Look out too for our exciting art competition with lovely prizes. We are looking for images for the website which illustrate what it is *really* like to have ME. Details on p 14. We also have the AGM announcement (p15). on 17th April and our very own Prof Norman Booth will be talking about research on the XMRV virus (*and* see p12.) and his own research on mitochondria and their role in ME. Other dates for your diary; Nicky's book group with a difference (p9), the Meditation group, as well as our other area social meetings. Details on the back page.

Most of our articles this time look at some of the ways we have found to cope with being ill, either with the help of a therapist or by developing what the DLA people call 'hobbies and interests'. Dot plays Dylan (p4), Hestia writes (p13) Nicky gets creative (p10). Other comforts; pets, bird watching (p6), listening to unfamiliar music, re-thinking the garden. Many ME people are enriched by learning to enjoy sitting or lying still in meditation.

Sometimes however help from a therapist is useful. Cassandra tells us about her progress with CBT (Cognitive Behavioural Therapy) on p.2 and Gill with counselling (p8). On the other hand Hestia was not helped and Susan found counselling damaging (p11). Of course there is a huge controversy and strong feelings about the particular use of CBT to help people with ME. Some patients have always said it made them worse. Jan has written a summary of some recent research showing why this may be (p6). The success of any psychological therapy (from psychoanalysis to counselling) depends on the relationship between therapist and client. If your therapist doesn't accept the reality of your experience then the process is not going to 'work'; Cassandra and Gill show when it worked well, 'Susan' where it did not.

This newsletter is the last one I am able to edit for some times. The next one will be an art edition - with the entries from our art competition and the chance to vote on your favourites. If you would like to be involved in this next edition, or with any other aspect of production, please email newsletter.omega@googlemail.com
Patricia Wells – Editor for this issue

STOP PRESS

Just as we were going to press came news of Kay Gilderdale's acquittal of attempted murder after helping her daughter Lynn to die. (We noted the generally sympathetic response of the media to this story).

<http://tinyurl.com/yekavun>. Lynn wrote very movingly of her life with severe ME : "*with every second of life in intense pain, feeling permanently and extremely ill, lying in a bed resting .. [with] 100 per cent reliance on others to care for my basic needs.*" ; and her considered decision to end her own life.

<http://tinyurl.com/y92w3uk> . See also *The Times* January 26th.

Our thoughts go out to Kay and her family and to all families struggling with severe ME.

CBT'ing is Believing

The story of one woman's journey through Cognitive Behavioural Therapy and radical pacing.

Before CBT

When I had been ill with ME for twelve years in 1997 I heard an OMEGA talk about CBT and graded activity. Like most ME people I had heard, at best, a mixed press about these techniques. I had already tried everything from working through it to complete bedrest, from acupuncture and homeopathy to intensive counselling, from diet to spiritual healing. Most had helped a little (if only in giving a feeling of direction and some hope). Diet helped a lot but nothing helped me make steady progress towards recovery. The talk impressed me with a programme of non-judgemental controlled activity, interspersed with rest, which would lead to a well-paced increase in capacity – and more: a hope of gradual recovery.

Eventually I had an initial assessment with a trained volunteer (a recovered sufferer at the then Harold Wood national centre for ME) before referral to the professionals. I was hugely challenged by the feedback that my current lifestyle was not giving my body a chance to recover from illness. My attempt at pacing – doing as much as I could, then resting for as long as it took – was, I was told, only perpetuating the exhaustion as I was always living at the edge of my strength.

I was introduced to the idea of finding a rested baseline of activity which meant I would not feel continually over-stretched and exhausted. Just finding this level of restedness sounded amazing – even if it meant cutting out most of what I did! The crucial thing was to feel rested from the last activity before starting another, and never to get too depleted that I couldn't rest because of the pains of exhaustion. Each day should have the same range of activity and rest; no more boom and bust; only doing one day what I could repeat on the next – and the next...

My volunteer explained: 'For people who've had ME as long as you (and longer), doing this regime will make you feel worse – as in less able to do things – for the first six months. You might well not see an improvement for eighteen months. But after two years you will begin to see a marked improvement and after five years you will have really turned the illness around.' It sounded difficult; I wondered if it was worth it but there was hope and having, literally, exhausted everything else I determined to try it.

How did it go?

I had to wait eighteen months before starting treatment in Oxford. But I already put into practice the radical regime outlined to me.

First, I cut out many things that had pushed me to my limit. Such as a one and a half hour yoga class, two-hour drive to see relatives, watching films, seeing friends for several hours, chatting on the phone for an hour and the occasional mile-long walk. The advice was to count TV as a taxing activity (!) so the daily limits went down to 15 minutes TV, one hour maximum with friends, 20 minutes on the phone, a five minute walk. Anything else I did for ten or twenty minutes and then rest for forty or fifty.

It sounds extreme to do this when I was able to do the other things – albeit at the limits of my strength and always at risk of relapse. However, I began to feel truly rested for the first time in many years, and even better, I was able to tell people what my limitations were, and to say 'No'. It was a profound relief to acknowledge that I really was that ill, and not to have to push myself and pretend to be better than I was. As I 'came out' as an ill person much stress and strain was lifted. I no longer had unrealistic expectations of myself, and others respected my illness as I explained what I was doing.

When I finally got to see the consultant psychologist at the JR she assured me first that as no one knows the exact cause of ME we were there to take away any obstacles that impeded my recovery. There was thus no battle for mind or body interpretations of ME.

Next, it would be a collaboration with my unique experience – not a timed set plan of recovery. I had 16 sessions over eighteen months – a gradual process of emotional discovery and learning how to gently do more without overdoing it.

What did I learn?

Acceptance

The importance of accepting myself as I am how I am, now. I could also explain ‘this lifestyle is my treatment because the fatigue is so abnormal’.

Timing

It was good to have a structure to the day, set times for getting up, going to bed and meals. Some activities and rest were best at certain times of the day. I learned to limit time on a task by sticking to the timing and not to the task. Changes of activities through the day kept my brain ‘fresh’ and not ‘tired of’ my life. Variety was the spice of satisfaction!

I became more predictable in my energy and could make commitments I knew I could keep.

Goal setting

Just identifying realistic and relevant personal goals gave my life direction. Then I learned to break the goals into stages, and paced myself to keep going on projects over time. With exercise I started with a 5 minute walk once a day and crept forward over 2 years to ten minutes.

Evaluation

I learned to cultivate more emotional awareness around my habits of living. I asked: ‘Am I still downplaying everything I achieve?’ ‘Am I meeting others’ needs before my own?’ and ‘Am I placing unnecessary demands on myself due to expectations from the past?’ I wrote a happiness journal about things I enjoyed.

Flexibility

Over time my capacity and so my goals changed. I could experiment with another level of activity and get comfortable with that before moving on further. Everything

gradually became more flexible and less precisely timed as I gained more energy. Rest too changed: from bedrest with no stimulus at all to low key activity sitting down with a cup of tea and a magazine.

So what happened over the next 12 years? The first two years were considerably more limited in activity, but then I started to feel I had more control of the illness; after 5 years I felt far more rested and in control of my energy. I was able then to do all the things I had been attempting in the boom and bust years, without relapse and without strain. I could socialise, I could go out for an evening, I could walk for 20 minutes, I could sew and paint for an hour or so.

Now I find myself a further 7 years on with a very good quality of life. My capacity very gradually increases year on year, though I cannot undertake a job. The main difference is in not having the soul-destroying depth of fatigue that I used to have. But, it has to be said, this process for me has been about accepting the parameters of ME and working with them to find a comfort level away from the constant strain and stress of overdoing it. The pacing has now become second nature and the ‘shoulds’ and ‘oughts’ of life before have become ‘yes, I can do that...’ or ‘no, I won’t put myself through that...’ and ‘maybe next year I can aim for this...’ Fundamentally, it’s not about anticipating total recovery, but about getting to the point of saying: this is my life, and it is good.



OMEGA members and friends enjoying the annual Christmas lunch

Dot Plays Dylan

A (very true) story by Dorothy Hillbeck. Written in July 2007 to commemorate my coming of age – 60 on 18th June 2007.

Let's face it; this illness has a bad habit of taking things away from you, and it's good at it! We take for granted all the things we can do until the day comes that we can't. M.E. erodes the ground you stand on a bit at a time, until one day you really don't want to think about everything you've had to give up. And each time something is taken away, it takes a little bit of you with it. So wouldn't it be nice (really nice) to claim something back! Well, in 2006/2007 I did just that. And so I am sharing my story with you – the story of how Dorothy taught herself to play the harmonica...

Since 2005 and returning to a wheelchair (again) I spent much time housebound, and in 2006, I heard on the radio 'Mr Tambourine Man' by Bob Dylan. Back in the 60's I was a Beatle-mad teenager and never gave particular attention to Dylan. But as I listened to his original version, I felt completely awestruck; the words, the music, the voice, the very texture of it. And I wondered why I'd ever liked the big hit cover version by the Byrds, when this original version was amazing.

In June 2006, the birthday fairy delivered a double Dylan CD and I spent the rest of summer hooked, listening endlessly to the master and his songs etching themselves into my soul. One day a silly thought popped into my head... 'I want to play along; I want to play the harmonica'. It made me laugh; it was a daft idea. I was a musical moron and couldn't read music.

The harmonica idea was dismissed; but try as I might; it kept coming back.

Could I do it? Nah! I had M.E. I was legless as well as brainless. I was pushing 60. If I tried, I'd fail. But the idea still kept coming back. Well, maybe I could give it a try; there was a chance I could do it; ... nothing ventured!

Lesson One – Which Harmonica?

Tips from the web:

The harmonica is also called 'the harp'? and there are two kinds:

The chromatic; all singing-all dancing; is very loud. Not recommended if you don't want to shatter eardrums of people living in nearby villages. Erm... no!

And the diatonic, also called the blues harp; only has 10 holes, small neat, can be practised waiting at traffic lights (as long as not driving); come in single keys and recommended for beginners. Oh, yes!

Lesson Two – Buy a harmonica

Ebay; the Swan (as in Vesta matches?) Diatonic 10 hole harmonica in 'C' (made in China), cost £5.99.

Lesson Three – Buy a Book

Internet music shop - 'Absolute Beginners Harmonica' £8.95. Large bold print and large pictures.

Lesson Four – Make a Start

More tips from the web:

Take the harp between thumb and forefinger with the numbers up and the holes toward you, put your lips on it and blow. Now suck. Now blow. Now suck. Sounds like two accordions having sex right? Try blowing and drawing through only one hole. Not so easy. Pucker up like you would to kiss your old aunt Ethel

In truth, you really have to wrap your mouth around a harmonica, getting it as far into your mouth as possible without losing it (and still maintaining the said important 'pucker').

In August, after two weeks of practising notes and scales (and puckering up), Derek took me to Southsea for the day. I took along my little tin sandwich and taught myself to play 'You Are My Sunshine'. I learnt it on the journey there and played it all the way back.

Lesson Five - Don't Buy a Cheap Harmonica

This should have been Lesson One, but I learnt it late. It wasn't my fault the harp wouldn't play high notes. Swan should stick to making matches.

Lesson Six – Buy a New Harmonica

Hohner 'Special 20' Diatonic 10 hole harmonica in 'C' (hand made in Germany), cost £18.91. Brilliant!

Lesson Seven – Overcoming the Drawbacks

Including flabby mouth muscles that don't want to work, and gasping for breath after two bars (as you play on the draw as well as the blow, the only time you breathe is through the harp). Someone pass the oxygen please!

Lesson Eight – Covering the Basics

Includes finally accomplishing 'puckering up' and being able to play single notes, hitting them right, and learning lots of pop tunes. Now into Christmas, so also includes Jingle Bells, Oh Come All Ye Faithful and Silent Night.

Lesson Nine – Accept your Limitations

Can only play in 'C' as still have only one harmonica. Still can't read music (never will I suspect). And for Gods sake Dorothy, stop playing Jingle Bells – it's February! Progress failing!

Lesson Ten – Get Help

Can't get to harmonica teachers out there. Email to the National Harmonica League brings the name of teacher Ren in Oxford who plays harmonica and says– buy a new book – 'Harmonica for the Musically Hopeless' by Jon Gindick (thanks Ren). (Thank you NHL)

Lesson Eleven – Read the Book

Hand Vibrato and TONGUING (rude I know), the Cross-Harp System and Riffs. I learnt to use my hands to mute, wah-wah and trill with hand vibrato. I learnt at last to use my tongue to 'te' out notes in quick succession.

Gindick says music is a river; winding around curves, rolling downstream. When the harmonica is in the river, it's playing a safe note of resolution. When it bends and twists,

it comes out of the water into the wailing note. The notes in between are the stepping stones that carry you across. (Oh well, beats learning music proper I suppose).

More tips from the web:

Q: How do I get to Carnegie Hall?

A: Practise, practise, practise.

Lesson Twelve – Buy More Harmonicas

Bought two more harmonicas – in keys A and D; could now play Jingle Bells in three different keys. Great (not!). Continued to practise, especially when cooking while the potatoes boil. Learnt more riffs.

But was I playing along with Dylan? No! Before I could do that I had to know what key he was playing in – there were 12 possible keys and I only had three of them. Working this out is worse than Sudoku (double argh!).

Lesson Thirteen (Lucky for Some) – Perseverance Pays Off

Listening to Dylan one day and his song 'Beyond the Horizon', I picked up my 'C' harp and tried a few notes; they harmonised. I tried a few more notes; some worked, some didn't. I listened to the band and tried mimicking their riffs; some worked, some didn't. I found the safe note, and ventured into a few stepping stone notes, (er... a bit slippery). Then I ventured out the water and gave it my all – a beautiful wailing trill – until I stepped down once more into the water and finished on a safe note of resolution.

I bought four more harmonicas and now had seven keys – C, A, D, Eb, F, G and Bb.

I trialled and errored until I found my 'Bb' harp worked beautifully with 'Spirit On The Water' and the 'A' harp with 'Workingman's Blues'. After a lot of trial and error: I could join in. I could jam with Dylan and the band. DOT WAS AT LAST PLAYING DYLAN and it was amazing.

On 17th April 2007, I sat in my wheelchair allocated space at the National Indoor Arena at Birmingham and at 7.30pm the lights went up to a man in a white hat and his band. It was Bob Dylan. And for over two hours I sat not

just in awe and wonder, but in gratitude to this man who had inspired me to take something back.

I'd not only learnt to play the harmonica, I had reclaimed a little piece of myself. In my bag was a little box and in the box was my harmonica, because it mattered that I'd brought it with me. And at the end when he took his final bow and left the stage, welling up with tears, I waved and shouted a big 'thank you Bob' because the inspiration this man had given me to overcome my illness and take something back, really mattered.

January 2010 – Update

So, did I stick at it? Or did the harmonica end up in a forgotten place at the back of a drawer somewhere?

Late 2008 I began a Blues Masterclass Programme incorporating 15 different books, cd's and dvd's. In 2009 I found myself a professional harmonica teacher in Bristol and attended my first harmonica workshop in Milton Keynes.

I've learnt how to bend notes in true blues fashion. And I play for over an hour a day, every day.

Whenever I hear a harmonica playing on the radio, I love it so much I could cry. And I know I will play harmonica for the rest of my life.

Oh joy! Go girl, go!



Bird watching from bed

CBT and GET: Another perspective

Jan Seed summarises a long and complex paper about two therapies. (We have put the full reference and a link to the original paper below.)

Two research workers (N.M.Twisk and Michael Maes) recently read 115 research articles from around the world and wrote a review of them. They looked at research on the use of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) in ME/CFS. Their evidence shows why CBT and GET may be harmful for some patients, and why they believe it is unethical to treat ME/CFS patients with these therapies, particularly if there is no other alternative offered.

The Research

The authors remind us that ME/CFS is classified by the WHO as a neurological disease. However, many researchers and practitioners of CBT/GET use the (bio)psychosocial model. Briefly, this holds that there are predisposing factors (e.g. genes, personality traits), triggering factors (e.g. infections, vaccinations), and maintaining factors (e.g. illness beliefs, stress, inactivity). CBT works to challenge illness beliefs and GET aims to increase activity. Each may also include elements of the other.

However, the authors also quote research showing that ME/CFS patients (without an accompanying psychiatric problem) do not have exercise phobia, nor does deconditioning seem to be a perpetuating factor. Neither are there any differences between patients with ME/CFS and those with rheumatoid arthritis in various personality traits - including perfectionism.

The (bio)psychosocial model has been shown to be applicable to people who have "chronic fatigue" due to a psychiatric condition; and thus, for these people, as for people with depression, CBT and GET may be helpful.

The Twisk and Maes' paper outlines some of the many physical abnormalities demonstrated in people with ME/CFS; and in particular the different effects of exercise that

we all know – e.g. the delayed & slow rate of recovery, the increasing inability with repeated exercise. They also document various abnormalities in many systems and parts of the body – e.g. immune system, muscles, mitochondria, and blood. In many cases the severity of the abnormality is correlated with the severity of the symptoms. Many of these biological abnormalities increase after exercise.

The paper then states that, whilst there are some trials showing that CBT or GET can be useful for some patients (our underlining); CBT/GET is not only ineffectual but actually harmful for a large sub-group of patients. They say: "*CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS*". Yet we know that both CBT and GET are common treatments for people with ME/CFS and "Chronic Fatigue".

Why is this?

It seems to me that part of the reason for this apparent contradiction may be in the methodology of the research. The successful trials often include many people with "Chronic Fatigue" of unknown or psychiatric origin, and exclude many people with ME/CFS who are too ill to attend the regular sessions at the clinic or hospital.

From the mass of evidence, the authors conclude that "*it is unethical to treat patients with ME/CFS with ineffective, non-evidence-based and potentially harmful 'rehabilitation therapies', such as CBT/GET.*" They suggest that at least full biological and functional testing should be done before using such therapies. (Such testing is usually not available from your GP at the present time, and the tests have often not been validated or generally accepted by the medical profession).

What should we do?

What can OMEGA members make of all this, particularly those who may be referred for CBT or GET? You need to make your own judgement, but here are a few things to consider. Perhaps, like any other medical

intervention, it is helpful to be aware of the potential benefits and risks, and weigh things up carefully, depending on your own individual situation.

As well as your ME or "Chronic Fatigue", you might also consider your general health. For example, exercise improves the functioning of heart, lungs, muscle and bones, and improves mood; and gentle exercise, within one's limits, can help stave off various complaints from constipation to osteoporosis. However exercising to exhaustion is likely to exacerbate ME symptoms, and may cause relapse. CBT has been successfully used to alleviate depression and anxiety. People with long term conditions (including ME/CFS) may become depressed. People do not always know when they are depressed - there is such a thing as "hidden depression", which has long-term tiredness (also known as chronic fatigue) as one of its symptoms. CBT has helped some people with cancer and other illnesses, including ME/CFS, to manage symptoms and cope better, although recent evidence does not show any effect on longevity.

However, no one ever claimed CBT to be the cure for cancer, or denied the physical reality of cancer because CBT can help some people with cancer. I believe that we need the same acknowledgement of the physical reality of ME, whatever treatment we decide to try.

References:

1. Frank N.M. Twisk and Michael Maes (2009) A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS. *Neuroendocrinology Letters* 30 (3):284-299

Link to abstract:

http://node.nel.edu/?node_id=8918

Link to full article:

http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/Twisk%20Maes%20CBT.pdf

or it can be downloaded from LATEST NEWS AND UPDATES section at:

<http://www.michaelmaes.com/>

Gill Harvey's Story



Gill Harvey who now works as a therapeutic counsellor tells her story of how counselling combined with nutritional therapy helped her recover from severe M.E.

I vividly recall Christmas Eve 2003. It was almost mid-night and I lay in bed listening to the church bells ringing with tears running down my cheeks. It felt as if my life had been totally shattered, normally I would be at church with my friends celebrating the arrival of Christmas but I had been severely hit by illness and was barely able to get out of bed.

Looking back now I realise that for many years I had felt constantly tired and had come to assume this was normal. Then I developed severe ear pain which did not respond to conventional treatment and as specialists could not find the cause it was implied that the problem must be 'all in my mind'. This was all very difficult to live with and, not surprisingly, I became depressed. However, one day I came across a book entitled *Candida albicans* and, as I read it, I became more and more convinced that I had found the cause of my problems especially as I had been prescribed many antibiotics in an attempt to

get rid of the pain. I tried telling my GP about this but was met with a brick wall so I visited a nutritionist who told me that a four week restricted diet, together with a specific supplement, would rid me of my health problems. Initially, I felt better but during the following months work got very stressful and the candida surged again. About this time I realised that there was an emotional component to the way I was feeling and I started seeing a counsellor to work on some of my issues which I had suppressed for many years.

Then I got a severe dose of flu which completely 'knocked me for six' and I found myself housebound, hardly able to get out of bed and in a wheelchair. I was in severe pain, lost three stones in weight in as many months and had absolutely no energy. I was extremely ill and desperate and yet conventional medicine was able to do very little although I did eventually get a diagnosis of ME/CFS. While I was too ill to travel my counselling was carried out on the telephone but my weekly sessions were a life-line and slowly, ever so slowly, I felt that I was making emotional progress even if physically there was no improvement.

Then some of the leaders from my church came around (with my permission) to pray for my healing. Initially nothing changed but then I found a nutritional therapist who used questionnaires and telephone consultations to work with people with candida and ME/CFS. The first questionnaire I filled in produced a very high candida score (no surprise!) so sugar, yeast, wheat and dairy were definitely off the menu as well as all pre-packaged food, and anything containing caffeine. She identified my weight loss as a possible gluten intolerance and within two or three days of coming off gluten I started to feel a relative improvement. She also discovered malnourishment (due to my gluten intolerance), exhausted adrenals a bacterial gut infection and a fat intolerance. As each diagnosis was made I felt my energy levels increasing.

I firmly believe that counselling and nutritional Therapy worked hand-in-hand to help me in my recovery from M.E. In counselling I was able to explore my emotional issues in a safe and non-judgmental environment while nutritional therapy built up my overall health and stamina. It has been a long and determined journey to where I am today (almost fully recovered and able to lead a very normal life).

So what is counselling? I like to explain it in the following way:

Many of us experience problems, difficulties or 'just discomfort' at some time in our lives. Often we have painful memories from the past, problems in our everyday lives or worries about the future. Counselling may help us with these feelings and assist us with new ways of coping.

My aim, as a counsellor, is to offer the client a confidential (with some rare exceptions), safe, warm and non-judgmental environment in which to share and explore inner thoughts and feelings. It is a process which aims to empower the client to find their answers by gaining fresh insight and enhanced self-awareness and to feel more in control of their life and relationships.

Counselling can help with a wide range of issues among which are, for example, abuse, anger, anxiety, bereavement, depression, disability, eating disorders, faith, illness, low self-confidence, low self-esteem, relationship difficulties, stress, trauma, work problems (including redundancy).

So convinced was I of how much counselling helped me that as soon as I was well enough I returned to College to complete my counselling training. I really enjoy the work that I do and I feel that my own experience of serious illness has given me a great empathy for those who suffer any illness but particularly ME/CFS. After all, I have a great deal of experience of what it is like to 'walk in the shoes' or indeed 'be in the wheelchair' of an ill person.

Gill Harvey:
www.gillharvey.co.uk

Further information:

British Association of Counsellors and Psychotherapists website:
www.bacp.co.uk

Counselling Directory website:
www.counselling-directory.org.uk

OMEGA Book Club

Nicky Williams lives in Bicester and wants to see more activities based in the north of the county. Here is her idea for a Book Club with a difference!

Having the illnesses we have, we all turn to different things to brighten up our day, and books are quite high on the list of activities. Reading is a wonderful way to escape from the world for a while!

My idea is for all of us who can to get together and chat about the book we are currently reading. The difference with usual book groups is that we don't all have to read the same book, so there is no pressure to get a specific book or read it on time. We all have different tastes and different speeds of reading. I am dyslexic and it takes me longer to get through a book. The main idea is to learn about different authors; I am always interested in hearing about different books, and hearing reviews of them. (I could take notes on each book we speak about, and what we think, so those who are not well enough to attend can have the latest details!)

Also I would like to offer people the option to give books away to one another. There are millions of books out there, I know once I have read a book, the chances of me having time or energy to re-reading it is non-existent, but I have this need to donate it to a 'good home,' and pass it on etc. I also need to go through my bookcase and really have a strict talk to myself, "will I honestly, honestly read that book again?" We have too many books in the house and need the space! You too? Maybe someone else has finished with a book you have always wanted to read.

This is for any OMEGA member, wherever you live; if you are too ill to drive and a carer/friend or relative can bring you they are

welcome to join in too. There is a bed anyone can rest on; stay as long as you are able. We can start the group at my home (which is small); maybe later meet in the local pub, maybe over lunch? I am happy what ever members fancy? The first meeting will be at my house: 34 LERWICK CROFT, BICESTER, OXON, OX26 4XL on Wednesday 24 February 2010 at 10.30a.m. and we can take it from there. Please contact me for details if you'd like to come on 07813 942474.

Time to get Creative?

Nicky Williams is our OMEGA contact in Bicester and she is enthusiastic about sharing her skills with us in crafts of various kinds. Nicky says: **'I have found art my way of coping with life in a constructive and positive way, and would love to share this with others.'**

I have always been a creative 'right brain' person and have always loved stitch, since I was 5 years old when I was taught to stitch a button on my rabbit's dress by a wonderful retired lady who lived in my street. When I was 6 my Godmother taught me tapestry and another elderly lady taught me the basics of knitting.

Later I trained and went into nursing so my artistic life got put on hold. Then I went into the army and then community occupational therapy. But then things changed and I was diagnosed with fibromyalgia and other associated illnesses and so I decided to use the opportunity to return to what I first loved – being creative!

I dabbled in watercolour, pastels, embroidery, acrylics and even teddy bear making. In the last 4 years I've also had the opportunity to study textiles art and design and other similar courses. I now do home study and I would say it's my life; it's what keeps me going. It gets my brain working and it's lovely to have a real passion for what I love best. It enables me to have a positive focus in life, which is really important.

I would love to share with others the life of creativeness and how it really helps gets you

through the good times as well as the tough times, and enables you to have a positive focus in life, which is so important. SO I am hoping to set up a group working with others, and through the internet and web cam for people who are housebound.

I would love to invite anyone, who would like to 'work' in any medium or anything to do with creativity. Many people are too ill to travel and I would particularly hate to exclude you. A video web cam on my laptop, if you are up for going on the net, means I could have 1 - 1 sessions with you. Even when the group gets together I could put up my laptop in the room so you can hear and see, and join in. You would need a microphone attachment to your computer or a headset.

Please do not worry if you are a beginner, or you dabble in cross-stitch, watercolour, paint by numbers, etc, you will be so welcomed. I would also like to invite others who have never done anything artistic, and would love the idea of having a go at something! My aim is to help bring us together and share and expand our creativity and knowledge.

People interested in forming a group can get in touch by ringing me or texting my mobile on 07813 942474. I aim to have the first meeting at my house in Bicester.



Susan's Story

Mary is very concerned about the effects of inappropriate psychological approaches including counselling. She tells us about her 18-year-old daughter's bad experience.

Some time ago Susan saw her health and well being plummet because of comments made by a counsellor. Susan wasn't sent there because of her ME but about other issues. The counsellor seemed very good for the first few visits. He knew that she suffered with ME before her first consultation. After a few visits he started leaning on her ME as her problem though that she wasn't sent to him for ME issues. He told her one-day - "You don't do things IN CASE you get ill afterwards". Susan came home distressed, angry, and livid. (Not half as livid as I was when she told me!)

She said, "Mum, I held my corner and told him that isn't the case and my teachers, etc. who know me know that. But he didn't listen". My daughter went down hill after that - she became depressed. She hasn't wanted to start anti-depressants, preferring to chat with her understanding GP. This is how dangerous just one comment can be from someone in the therapist role.

Susan has always wanted to be "normal", to get out and do things and has always done her utmost to achieve. This dangerous man hasn't a clue, yet can make comments that cause such upset and pain, not only to the sufferer but to all who know Susan. Needless to say she isn't going back again. This is not the first time that this young person has been belittled and made to feel worse by believers in CBT i.e. counsellors.

To put this in context: Susan achieved her bronze medal with distinction when doing oral drama lessons at home. She was asked by her tutor if she would like to help out with stage management and costumes in his show. It was a daunting challenge. She still used wheelchair most of the time when out. Very nervously Susan went along. It turned out she did two afternoon and 3 evening rehearsals and 4 nights at the show. Yes, she pushed her

body and knew she would suffer afterwards and she is, believe me, but tell me - IS THIS THE GIRL THE COUNSELLOR WAS TALKING ABOUT? THE GIRL WHO SUPPOSEDLY WON'T DO THINGS IN CASE SHE GETS ILL AFTERWARDS???

She WANTED to do this, wanted normality and thoroughly enjoyed every minute, despite the fear of any payback.

This is just how dangerous some counsellors/psychologists can be.

I dread to think what consequences such careless comments could have on a sufferer who had no one at home to support them. It truly frightens me.

Note: the names used in *Susan's Story* have been changed.

OMEGA has a new website!

We are very excited to announce the launch of the OMEGA website:

www.oxnet.org.uk/omega

If you have access to the internet, do go and have a look, and let us know what you think. Even if you do not have internet access, recommend this website to friends and family to aid their understanding of ME.

The main Omega home page includes details about the groups in different areas of the county. We have sections on Useful Publications, Joining Omega, Forthcoming Events, ME Support and Treatment, What is ME?, and Practical and Financial Support. We have lots of interesting pictures. You can even download past editions of the newsletter.

We would like to offer our heartfelt thanks to Kim Francis, the volunteer from Oxford Brookes University who has been working very hard to produce such a fantastic site. This puts Omega firmly in the electronic age, and we hope that it will attract new members to Omega, as well as providing a good service to existing members. Bookmark www.oxnet.org.uk/omega to keep up to date.

Free Website Access

If you cannot access the internet from own home there are places you can go to get a free connection to the Oxford City Council website, Oxfordshire County Council website, Directgov website, Thames Valley Police website and the NHS Choices website. Here are the Internet Kiosks around Oxford city. There is no need to book, just go along to the following locations during office hours:

Town Hall Reception St Aldate's Oxford OX1 1BX	Oxford City Homes Reception Horspath Road Oxford OX4 2RH
Ramsay House Reception 10 St Ebbe's Street Oxford OX1 1PT	Museum of Oxford St Aldates Oxford OX1 1DZ

You can also use computers at most public libraries and:

Barton IT Hub, Neighbourhood Centre,
Underhill Circus Barton, OXFORD,
OXFORDSHIRE, OX3 9UL, Tel. 01865 751616

Other help is available from Race Online 2012 (0800 771234) which can direct you to your nearest UK Online centre where you can learn the basics. (The website for this is www.raceonline2012.org)

XMRV and CFS/ME

Professor Norman Booth explains the recent news about XMRV

The publication last October of the scientific paper "Detection of infectious retrovirus, XMRV, in the blood cells of CFS patients" has created world-wide interest. It is too early to say if this virus is the cause of ME but it certainly seems to be associated with it. I won't speculate about this; the ME Association has already put at least 4 different versions of its medical adviser's views on its website. I will concentrate on how XMRV might relate to the mitochondrial dysfunction that I know something about.

Like the AIDS virus HIV, XMRV is a retrovirus which can enter cells and attach its RNA to the DNA of the host cell. The host cell DNA then has the recipe book to make the proteins of the virus, allowing the virus to be replicated and spread to infect other cells. As long ago as 1991 it was shown for HIV that certain cytokines involved in the immune response can stimulate the replication process, but intracellular antioxidants such as glutathione can prevent replication and thus maintain a state of viral latency. How does this happen? Replication needs the synthesis of viral proteins and their assembly according to the recipe book. It is often overlooked that this process requires energy – namely energy from the ATP produced by the mitochondria in the host cell from oxygen and fuel, such as glucose, transported by the blood stream. The protective response of the cell is to adjust to a state with less production of ATP and therefore lower energy production. If you have ME, your immune response is poor and you already have less energy production. This may be a safety mechanism to inhibit replication of the virus.

For the first time things are moving fast in the area of biomedical research into ME, but understanding will take time. While you are waiting for a cure, there are some things that you can do now. Doctors such as Sarah Myhill in the UK and Paul Cheney in the USA recommend avoiding highly oxidizing factors such as diets high in sugars, fructose, processed food and allergenic foods, environmental exposures to contaminants especially mercury, and immune activators such as vaccinations, mould and stress or chaos in your life. Factors that are antioxidantizing and therefore protective are fresh vegetables, freshly juiced green drinks, olive oil, clean environments and low stress.

I will give more details and news of further research in my talk at the OMEGA AGM on 17th April.

Norman Booth

Who is Hestia?

Hestia's occasional column 'View from Indoors' has appeared in the Newsletter for some years. Here's how she got one of our members through.

I got ME many years ago and was very ill. I'd worked teaching, researching and writing; I travelled a lot for work. When I got ill I lost job, mobility, colleagues, lover and many friends. The family were all grown up. For five years I hardly left the house and felt lonely and depressed; a familiar story. In those days no-one quite knew how to help – eventually I was well enough to see a hospital psychologist - who patronised me and really wasn't any help.

Meanwhile I'd tried to help myself; pacing, diet, acupuncture, naturopathy were all helpful. I tried to think in a different way about my predicament and hit on trying to use images and metaphor, what you might call the 'right brain' rather than the problem-solving and verbal 'left brain' approach which came more naturally to me. I noticed I always felt worse in the winter and came across the story of Persephone. In Greek mythology she disappears into the earth for three months of the year, symbolising winter and withdrawal from everyday life. As I was doing that perforce in this illness, particularly in winter when I hardly saw daylight I identified with this archetype. I started to write a thoughtful annual solstice letter to go with my Christmas cards and wrote about this myth in the first one. By this time I could just about sit at a friend's computer for five minutes before having to lie down.

Thinking about Persephone led me to a book, based on Jung's idea of archetypes, which shows how as women we can identify with one of other of the Greek goddesses in terms of our roles and activities. (There is an equivalent book about the male archetypes.)

For example, Artemis is goddess of the hunt, symbolising the active working competitive aspect of life. (I'd done this bit in my career, but clearly couldn't now.) Likewise Hera (marriage) and Demeter (nurturer and mother). Of the others, Hestia and Persephone caught my attention. I couldn't quite identify with the total withdrawal of Persephone, but Hestia, solitary goddess of hearth and home, rang a bell, since there I was stuck at home sitting by the fire. Scary though, I wasn't enjoying solitude much.

Back then I was asking myself what I could do with the very limited energy I had, and how I could learn from this horrible experience. It just had to be an opportunity for something that I wouldn't otherwise have had. I didn't think the universe was trying to teach me anything; I think stuff happens and we have to deal with it, and try to learn from it, even if it's just how to accept the s***. I learned that there is a place for just sitting and feeling the aloneness; that it is not the end of the world.

I'd always wanted to write more; at this stage I could just sit up in bed with a pencil and paper. So I decided to try and find my voice, my writing voice, and on the way to try to express what it was like to live indoors, to perhaps to be a reporter to the rest of the able-bodied world what it was like living as I did. So I chose Hestia as a nom de plume, writing from that indoor solitude.

Soon I looked out of the window, at the view of my garden, and thought about transforming that too. But that is another story.

* Jean Shinoda Bolen *Goddesses in Everywoman* by. Harper & Row 1985

Jean Shinoda Bolen *Gods in Everyman: Archetypes that Shape Men's Lives* Harper & Row, 1989

Art Competition!

Be creative! Win prizes worth £100!

This is the chance for you to release your creativity, and show the world what it is *really* like to have ME, You will also have the chance to have your art work put in an exhibition in Oxford artweeks, and for it to be displayed on Omega's web-site and in the OMEGA newsletter. On top of that, we have 3 fantastic prizes for the best entries. So what are you waiting for? Give it a go!

Closing date: 31 March 2010.

We are looking for original art work that best represents "**What is ME?**". We have the description of symptoms etc. on the web-site: www.oxnet.org.uk/omega, but we want to have art work showing what it means to you. Don't feel limited, you can show any aspect of ME, including any symptoms or effects to sufferers or their friends and family, or how people with ME achieve despite their illness. The art can be in any medium.

THE PRIZES:

1st: £50 voucher kindly donated by Spirit of Nature.

Spirit of Nature is a web-based and mail-order company specialising in organic clothing, toiletries and natural cleaning materials, plus a good range of children's items. www.spiritofnature.co.uk 0844 801 9885

2nd: £30 voucher kindly donated by Riverford Organic Vegetables

Riverford supply a wide range of local organic vegetables, fruit and other organic goodies by home delivery. You can order online or by phone.

www.riverfordnorton.co.uk 0845 600 2311 / 01803 762059

Special prize: (*Open to OMEGA Members only*) £20 in cash

Competition details

Open to anyone who lives or works in Oxfordshire.

You can put up to 2 entries in the competition, but if space is limited, only one entry per person will be allowed in the exhibition.

The art work can be in any medium and should be less than 1000mm x 1000mm (39.5" x 39.5"). We need a good quality digital photo of the original work, and also arrange for it to be delivered to East Oxford in April.

The competition will be judged by Omega members

SEND OFF FOR FURTHER DETAILS NOW - this doesn't commit you to anything -

email: omega.competition@googlemail.com

OR

Write to Omega Competition, 19 Maidcroft Road, Cowley, Oxford, OX4 3EN, enclosing a stamped addressed envelope.

Your details will not be saved or used for anything other than the competition.

It will help us if you could send off for the details as soon as possible so we can get some idea about number of entrants. Thank-you.

Exhibition Details

The exhibition will be from 1 - 29 May, (not Bank Holidays), Mon - Sat, 9am-6pm, at the Magic Cafe, Magdalen Road, East Oxford, OX4 1RQ. It is a lovely relaxed space with good vegetarian food. We will have an OMEGA social there on Saturday May 29th at 3pm to celebrate and award the prizes. You will also be able to collect your picture at this time.

OMEGA AGM and talk

Saturday 17th April 2010 2.30pm - 4.30pm

Regal Community Centre, Ridgefield Road, Oxford, OX4 3BY

"XMRV, mitochondria and ME: are they linked?"

by Norman Booth, recent co-author of a research article on mitochondria and ME. This will be a look at some of the exciting new developments in ME medical research, and should be very interesting.

We will have a very short AGM (about 15 - 20 mins.) followed by Norman's talk and questions. Refreshments will be provided in the break. Please bring a mat and cushion if you would like to lie down (uncarpeted floor).

Please note new venue.

Regal Community Centre, Ridgefield Road, Oxford, OX4 3BY

www.regalcommunitycentre.org.uk

Directions (see map below):

Bus: From Oxford: No.5, 1, 10,12 or U5 along the Cowley Road to bus stop between Kenilworth Road and Cumberland Road. Cross over the road and walk away from town for about 50 yards. Take the footpath on the right. This leads direct to the Regal Community Centre (next to play area) (approx another 50 yards).

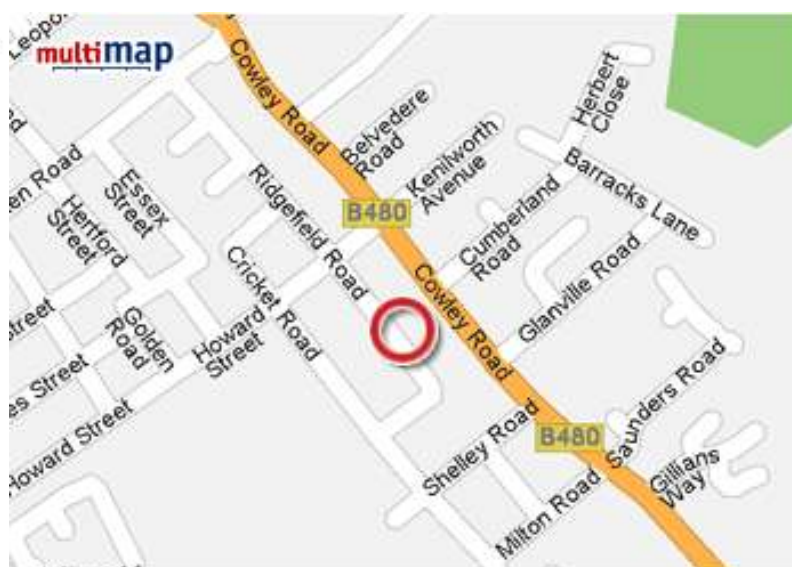
Car: From Ring road at BMW Mini works roundabout, Cowley, take the B480 Oxford Road Cowley, which turns into the Cowley Road Oxford. Just past Glanville Road (tattoo parlour) turn left into Howard Street then***

From Oxford, take the Cowley Road towards Cowley. Go past the Regal night club (Old Bingo Hall). Turn right into Howard Street then ***

*** **(from all directions from Howard Street)** 1st turn on the Left (Ridgefield Road). The road bends to the right and the community centre is on the Left on the corner, just before the play area. There is ample parking outside. It is wheelchair accessible.



"Everyone here? Good. Meeting topic: Setting world record for shortest meeting. All in favor say aye. Ayes have it. Meeting over."



Diary Dates

24 February 10.30am Book club Ring Nicky Williams 07813 942474
 26 Feb OMEGA meditation. Ring Jan Seed 01865 718274
 8 March S Oxon Social Group, Waterfront Café, Benson. 12midday to 2pm. (Ring Tessa Keys 01491 838727) On Oxford to Reading bus route. All welcome.
 26 March OMEGA meditation (TBC ring Jan Seed for details)
 17 April **AGM** 2.30pm - 4.30pm Ridgefield Road Regal Community Centre. Oxford, OX4 3BY
 1 May Opening day at "What is ME?" art exhibition Magic Cafe
 24 May liME International conference Westminster
 25 May possible visit of Dr David Bell. Details from Norman Booth
 29 May OMEGA social 3pm to 5pm Magic Café, Magdalen Road, East Oxford and take down art exhibition
 FIRST MONDAY of EVERY MONTH **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.

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: ltr13@tiscali.co.uk

OMEGA Website: 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

OMEGA Volunteers

Competition	Jan Seed	01865 718274
Chairperson	Patricia Wells	01865 554648
Treasurer	Helen Garfitt	01844 298619
Meditation Group	Jan Seed	01865 718274
Membership Secretary	Lesh Lender	01865 766310
Publicity	Pauline Hammond	01865 719340
Wantage contact	Annie Kingsbury	01235 763813
Clinic Group Contact	Norman Booth	01235 833486
OMEGA rep. for OCCMET	Janet Proudman	01865 723764
Banbury Contact	Karen Finn	01295 272119
Bicester Contact	Nicola Williams	07813 942474
Witney and 'Invest in ME' Contact	Flora Mckenzie	01993 774834
South ME/CFS Support Group	Oxfordshire Tessa Keys	01491 838727
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, Nathan Smith, Patricia Wells. Email address 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.