



Welcome to Our March 2012 Newsletter

A Note from Alex: I can't believe that it's that time of year again, I can hear you all wondering what I'm on about, I'm afraid to tell you all that its Membership renewal time again. You will find enclosed with this month's newsletter our Application Membership/Renewal Form and our Group Membership survey. Please note that we have had to change the times of our weekly yoga sessions again to 2.45pm – 4.00pm. I hope you enjoyed the

Sudoku puzzle that I made up for you last month, the solution can be found on page 7. Lastly please don't forget that on the 15th March it's our AGM at Longsight and we look forward to seeing you there.



Emmy felt that her GP didn't take the severity of her symptoms very seriously.

With thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

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DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Bury/Bolton ME/CFS Support Group & Sponsors

www.mesupportgroup.co.uk

The Bury/Bolton ME/CFS Support Group was founded in September 1990 and is managed by a committee of six members: Pam Turner, Margaret Benn, Ann Richards, Maria Sale, Sheila Myerscough & Kim Finney.

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Supported by:
**Health for Bolton and the
Big Bolton Fund via Bolton CVS**



Dates For Your Diary

Longsight Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane, Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

Thursday 15th March – AGM. We would appreciate it, if as many of you can attend the AGM in order to show support for the committee and our support group in general. The AGM should last about an hour at the most. Don't forget that we will also be holding a raffle. For the full information & Agenda please refer to the leaflets that were enclosed in last months newsletter.

Please note that there will be no meeting in April.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 2nd April at 4pm, at The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY.** It has plenty of parking, good accessibility; comfortable seating is relatively quiet and serves very tempting chips that we just can't resist. For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. For more information please phone 07919 234256 or email dave@mesupportgroup.co.uk. **Don't worry about getting to the venue and not being able to find us – just phone 07919 234256 when you get there and we will find you!**

Yoga Classes: Are **2:45pm-4:00pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX.** Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 07746 197511, or olivia@oliviayoga.co.uk for more information.

Neuro Support Groups: These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about meeting times and locations.

IF YOU ARE THINKING OF ATTENDING ANY OF OUR SOCIALS, WHETHER YOU ARE A NEW MEMBER OR A MEMBER WHO HASN'T BEEN ABLE TO ATTEND FOR A WHILE, PLEASE REMEMBER THAT YOU CAN BRING ALONG YOUR CARER OR A FRIEND. WE DON'T BITE, BUT WE UNDERSTAND THAT MEETING NEW PEOPLE OR IF YOU HAVE BEEN HOUSE BOUND FOR A WHILE, IT CAN BE QUITE DAUNTING GOING OUT BY YOURSELF AND WE'LL LOOK FORWARD TO SEEING YOU.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANKYOU.

We would like to say a big Thank You to Mrs Marjorie Fielding from the Get Away Club, as they have kindly made a donation of £50 to our Support Group. Thank You again, as this donation will help to keep our Support Group running.

Bury/Bolton ME/CFS Support Group Meeting

February 2012

This month we had in affect 2 speakers, Amy Davis from Forever Living and Professor Chew-Graham from Manchester University.

Amy Davis from Forever Living:

Amy came to tell us about Forever Living, a company which markets Aloe Vera products.

She told us a little about herself and how she came to work with Aloe Vera. After working in recruitment for 10 years Amy was eagerly looking forward to attending a family wedding but also apprehensive because of her size. Wanting to look her best she managed to lose 12 stone naturally, but this left her with lots of loose skin. Amy then underwent surgery to have skin tucks and to stabilise her abdominal muscles. She started using the Aloe Vera products to help her stomach heal and now she said that she lives by it. It gave her relief from the pains in her stomach and it settled down so that she felt much better.

She then introduced us to her friend Gabby who told us that she had been diagnosed with cancer and when she used Aloe Vera she felt that it had helped her. Gabby said she feels safe with Aloe Vera as it is a natural product. She is now setting up a cancer victim support group and will use the earnings from Forever Living to keep the group going.

Amy then told us a little about the company which is American owned. They have patented a cold stabilising process in which only 2% of the natural goodness is lost, making their product 98% pure. The main product is a drinking gel, made from the inner leaf, which is anti inflammatory and acts as a detoxing agent and immune system stabiliser. She said that it is an unbelievably great product which has a compound of naturally occurring vitamins and minerals in small amounts, but the body takes what it needs and because they are water soluble, any excess is flushed away. She described it as an immune system balancer and anti inflammatory and said it is good for the skin, also because the body is working well it helps to raise the mood.

One of Amy's friends suffers from fibromyalgia and since she has been using Aloe Vera has been able to come off morphine and can manage with lesser addictive pain killers.

Amy went on to say that 98% Aloe Vera has a strong taste, which not everyone likes, so the company have several other Aloe Vera gel drinks which are flavoured e.g. Aloe Vera Nectar which is 86% plus cranberry and apple, also Bits and Peaches which has small pieces of Aloe Vera and which tastes of peaches and is more acceptable to children. There is an Aloe Vera Forever Freedom which is 96% plus chondroitin plus glucosamine so it is good for active people e.g. Athletes but also for helping to repair joints. Amy said her father takes it, also her friend has a horse which was so lame it was to be put down but after using this product is alive and well.

Amy also recommended bee pollen tablets which give a boost of energy and raise metabolic rate. She said it helps people who don't sleep well by giving them more energy to keep going during the day so that they sleep better at night.

Amy had lots of other products containing Aloe Vera e.g. Deodorants and creams which also contained propolis, which is a natural antibiotic so that it is good for rashes and it moisturises dry skin. There is also an Aloe Vera jelly which dries up oily skin and is good for treating acne and is good for cuts, burns and cold sores.

MSM is a natural sulphur product which goes deep into the skin, down to the joints to relieve pain.

There is also a deep heat lotion containing both capsicum and chillies, which relieves muscular pain without burning the skin.

Other products include a liquid soap, shampoo and conditioner, toothpaste and a lovely relaxation massage lotion of lavender and bergamot and even a perfume.

They also now have a cleaning product called MPD, which does not contain harmful agents such as bleach and can be used on mirrors, floors, all round cleaning and even for washing clothes.

Finally she told us that the lip cream is good for moistening lips but also effective on cold sores.

Amy can be contacted on Tel no: 01829 740995 or mobile 07851 874239 or by email amydavies_foreverliving@hotmail.com

Professor Chew-Graham update February 2012

Professor Chew-Graham came to give us an update on the METRIC research being undertaken by her team at Manchester University.

She explained that METRIC follows on from research done over 5 or 6 years in the FINE trial, which aimed to see how ME was managed in Primary Care (GP Surgeries). They found that patients were not happy with the care given and that GPs were not sure how to help.

Then 31/2 years ago, she and the team applied for funding and she thanked Pam for agreeing to be on the research team and supporting the grant application. They were granted the funding 2 years ago and Pam and Yvonne have been on the management group overseeing and helping with the development of resources to help GPs to offer a better service to ME sufferers.

They have also set up 2 service user involvement groups who have told the team of the problems that they have encountered and also highlighted the needs of carers; they have also interviewed many sufferers.

She told us that although many GPs don't know about ME they do not have the time to undergo long training sessions. The METRIC team felt that the best option would be to develop an e-learning programme for GPs and a folder with a DVD and leaflets for patients. They felt that it would be easier to watch a DVD than trying to read, all the information on the DVD is directly from patient input groups.

Now that the packages have been developed, the next 18 months will be spent working with 5 practices in each of 3 areas-: Bury, Stockport and Central Lancs (Preston). They will give the information to the GPs for their patients and ask them to evaluate it using questionnaires to see how useful it has been.

At the end of this time there will be a full evaluation of all the materials to ensure that they are as good as possible and any modifications can be made to ensure that they are useful.

Professor Chew-Graham assured us that this project has been led completely by patient's views and has used a bottom up approach.

Everyone was very interested in the project and was very pleased that Professor Chew Graham had managed to come to tell us about it.

Time for Action to End Ignorance, Injustice and Neglect. **Action for ME Email Update 7th February 2012.**

Action for M.E. has launched a new campaign, Time for Action www.actionforme.org.uk/get-involved/campaign-for-change/time-for-action, calling for an end to the ignorance, injustice and neglect of M.E., once and for all.

Far too many people still don't understand that M.E. is a chronically disabling condition that wrecks people's lives. No other illness with such a devastating impact on so many people has so little money spent on scientific research or the provision of specialist healthcare.

In the UK, successive governments have shown little interest in doing anything, and too many of those most severely affected by M.E. are simply left alone, isolated and abandoned by the medical profession and social services alike.

Many voices can force change; we need to get the first 10,000 people to register their support as soon as possible. Please help to spread the word about Time for Action by joining this vital campaign and sending this newsletter to your family and friends, asking them to register their support www.actionforme.org.uk/get-involved/campaign-for-change/time-for-action/i-agree-its-time-for-action.htm for this vital campaign.

You can also add our twibbon <https://twibbon.com/cause/Time-for-Action-2> and support the campaign on Facebook www.facebook.com/actionforme and Twitter <https://twitter.com/actionforme> Together, let's end the ignorance, injustice and neglect of M.E., once and for all.

Personal Independence Payments

If you're worried or confused about the proposed changes to DLA, the DWP released two documents on their website in January which explains things: <http://www.dwp.gov.uk/docs/personal-independence-payment-faqs.pdf> They also detail the proposed eligibility criteria and list two ME/CFS case study examples, which may give you an indication of the award you may get: <http://www.dwp.gov.uk/docs/pip-assessment-thresholds-and-consultation.pdf>

The guides are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge, plus use of the Freedom of Information Act. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal.

The group's subscription allows us to make these guides available to our own members for FREE.

If you can get to our meetings, socials or yoga classes, you will be able to pick the guides up in person. Alternatively we can email them to you - if you do not have internet access yourself, perhaps a friend or relative could help out.

Please note that we will only ask you for a donation if we need to post the guides out to you - this is because some of the guides are rather lengthy (number of pages in brackets below). For example it costs us £1.50 to send 20 pages to you, £2.50 for 40 pages, £3.50 for 60 pages and £5.50 for 100 pages etc. Please Contact Phil Seddon Tel: 01204301713 or phil@mesupportgroup.co.uk for more details

Cruel Comments Should be Reported – by Jane Colby Tymes

Trust Email Update 29th February 2012

Over the last week I have shared with my followers on Twitter some of the things that have been said to children with ME and their families. I have of course anonymised them. Judging by the reaction and all the re-tweeting that has been going on, people are amazed that these statements could have been made by professionals. Unfortunately, such occurrences don't seem to be as rare as we'd like to think. I have now decided to collect further examples. This is because, when I was planning to include an example in a presentation to the All Party Parliamentary Group on ME, I was asked by another ME organisation to avoid giving the impression that this was a common event. Well, having reviewed some of our Advice Line Records, I'm not convinced that it is all that uncommon. My brief review revealed the following: A professional arrived at a mother's home and told that her child with ME would be taken into foster care and that she herself would be put in prison with murderers and rapists if she didn't send her child to school. A doctor told a school that winter typically makes people with ME worse, but the reaction from a member of school staff was to say that the family should just get a light box. The 'sleep police' are ordering children with ME not to take naps if they feel they need them. Some of these professionals are well-known in the ME field and should surely know better. The late Dr Alan Franklin described forcing sick children awake inappropriately as 'cruel' as well as unproductive. And then we come to the extreme comment that I included in my APPG presentation: A child needing a wheelchair was told by a doctor that her legs might have to be cut off. This was not only a breathtaking lie but it must have terrified the child. I would class this comment and others like them, as a form of abuse. Of course, such comments also reveal a serious lack of knowledge about ME. For example - as ME expert Dr Elizabeth Dowsett always explained - having the option of a wheelchair can not only help a child get out and about, but also rest the leg muscles so they have an opportunity to heal. I remember a young girl who found the muscles in her arm stopped working. All she had been doing was over-using her arm muscles by typing on the computer too long. When she rested them, her arm function returned.

Dr Dowsett often used to point out that the muscles of someone with ME do not function like muscles that are fit and well and they need time to heal. Information on this is in 'Physios urged to

go cautiously', a letter of mine that was published in Physiotherapy Frontline. You can read it here: <http://www.tymestrust.org/pdfs/physiosguide.pdf>

I would advise parents to report professionals who make such remarks as those I have listed. Whether they spring from frustration at not being able to cure the child or from annoyance that the child seems to them uncooperative, these remarks are inexcusable. Do send me any comments which you wish to bring to my attention. It is important that we are armed with the facts. We cannot just turn away in embarrassment at the behaviour of the professions with whom we are trying to work, and pretend that this is not happening.

Jane Colby FRSA, Executive Director, The Young ME Sufferers Trust, PO Box 4347, Stock, Essex, CM4 9TE www.tymestrust.org Tel: 0845 003 9002

Optimum Health Clinic Website Offer — by Tracy Morris.

Optimum Health Clinic (run by Alex Howard) are offering full access to their M.E./C.F.S/FM website for 14 days for £1. The site offers over 100 hours of downloadable material re the research, techniques and lifestyle management that the Clinic believes may lead to recovery. Visit www.secretstorecovery.com for further details.

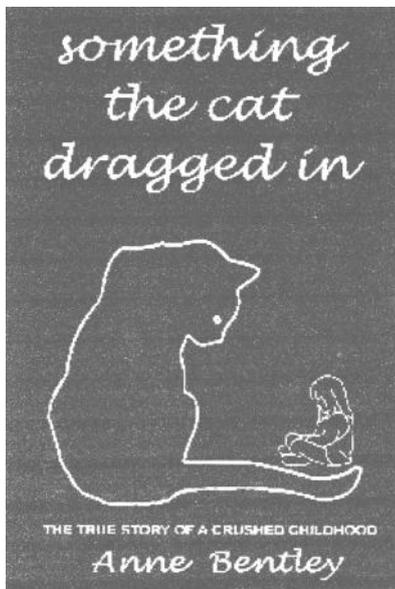
You sign up to the scheme for £1 using Paypal, then must set up an account agreeing to a £97 charge (which you are free to cancel during your trial period) and which gives you the option of having lifetime access to the site. This agreement is scheduled to begin after your two weeks access and Optimum Health stress that you are free to cancel this second payment within that period with no questions asked. I can confirm that it is genuinely possible to get all the info downloaded from the site within this time (i.e. for only £1), although it does take some determination!

The website is divided into 4 main subject areas: Nutrition, Psychology, Emotional Freedom Technique and Meditation. Each area is then divided into several modules with individual video clips dedicated to specific topics that the Optimum Health team believe will be helpful to patients generally. The site is easy to navigate and to use. Each video clip on the website has a downloadable transcript and/ or MP3 snippet. Once downloaded these allow access to the info after the 14 day trial which would be essential if you wanted to take your time over researching the subjects. It would also allow you to put any interesting info onto a memory stick or MP3 player to be used as and when required.

There is a huge amount of info on the website directed towards helping recovery or just giving suggestions for areas where further research may be useful (although there is also quite a lot of waffle at times too!). There are many recovery stories featured where people tell how they became ill, their thoughts and feelings, problems they encountered, and how they achieved recovery. Also available are downloadable CDs for relaxation plus the Optimum Health Clinic's 90 Day Programme Home Study Pack (to name but a few).

I was initially unsure whether this would be useful but found much of the info interesting. I am currently working my way through the first section (Nutrition) which has taken quite a long time, but despite all my previous research in this area, plus many consultations with nutritionists etc have found that there is info here that has been helpful. The advice can only be general (we are all very different after all), but looks at how specific groups of patients may respond to certain treatments, highlights research, caused me to do further reading elsewhere, and led me to alter my own regime. I am only beginning to work through this resource but am cautiously optimistic that among all the generalised info there are important pointers that may be helpful. At the very least I have found it inspiring to learn how so many people have beaten their M.E. and gone on to lead full and active lives, and also how they set about achieving this. It is very rare to get such an insight into so many recovery stories with so much optimism and practical help in one place. I plan to continue working through the rest of the site and learning more about how best to help myself. I hope that if you choose to take a look you may find it useful too.

1	3	4	2	6	5
5	2	6	3	4	1
2	4	5	1	3	6
3	6	1	5	2	4
6	5	3	4	1	2
4	1	2	6	5	3



Book Review by Alex Wootton

When Carole Brown first got in touch with me to, tell me that she was a member of our support group, that she'd written a book and would I be interested to put a little bit about it in to our newsletter, I'm sure after she got off the phone from me that she thought I'd dismissed her, as I don't think I was very receptive (as on that day I know that I was still waiting for my brain to wake up). The thing that sticks in my mind was the title of the book "Something the Cat Dragged in" and I remember saying 'oh what a nice title'. Anyway we got off the phone and a couple of hours later (after a couple of mugs of strong coffee) I called her back and explained this.

Of course after a general little chat she started to tell me about the book. It had taken her 9 years to write the book; with having bad health and ME on top of this I think you'd agree that she'd managed

something most of us with ME just wouldn't be able to get our heads around. Then she told me what her book was about, well I have to say that I could have fallen through the floor, as I listened to her telling me that she had written the book about her harrowing childhood. Harrowing isn't actually a strong enough word, as she was emotionally and physically abused by her mother and in looking for love from other members of her family found herself being sexually abused by her uncle. Below is my review of her book as I felt I had to read it before I wrote about it.

We all know how very cruel some human beings can be to one another, but to inflict such cruelty to one of your children seems so very wrong. But in the 50's & 60's life was very different from now: children didn't have any say, people like teachers who are now told to take note of how the children behave and interact weren't told to then and Child Line didn't exist. There was just nobody to stand up and fight for them.

As you will find in the pages of this book, some children have such an awful childhood, one that you wouldn't wish on your worst enemy. Carole is the eldest of 3 with a younger brother and sister, but for some reason, unknown even to this day, why did her mother pick her out and treated her in such a despicable way? There are so many things that happened to her but one part that really stays with me after reading the book is the following: It's was as she said 'I had not yet reached the ripe old age of eight', and one of the worst winters in the North West of England, snow had fallen a few days previous but there had been no thaw and the temperature just plummeted turning the snowdrifts into solidly frozen obstacles for cars and pedestrians alike, even so she had been sent to the shop for a loaf of bread, but was unable to make it due to the adverse weather and not having the height and strength to negotiate the huge expanse of snow'. So when she went home empty handed so her punishment began. 'Her mother was beside herself with rage, the corners of her mouth twitching with pleasure at the thought of what she was about to do.' Her mother threw her out of the back door without her coat; she was only wearing sandals and a thin dress, and was numb and cold from trying to get to the shop. Her mother did let her in when another member of their family came to visit and she was instructed to make a cup of tea and coffee, something that she had never done before. Unfortunately things didn't go to plan in making the drinks and after she had remade them and tidied up the mess she was thrown out in to the snow once more. This is bad enough but she was left outside for such a long time that 'I slowly slipped into a state of frozen stupor, I don't remember how long I was left out there, almost shivering to death, in the sub-arctic conditions, nor can I recall *who*, eventually, brought me indoors', I'm surprised that she didn't die of hyperthermia. If you would like to read this book for yourself it can be found on www.Amazon.co.uk as an e-book under the pen name of Anne Bentley. Carole gave me permission to use her real name for this article. Carole, I think that you are a very brave and courageous woman to have written this book, as you'll have had to relive everything that happened to you and I also know from talking to you that you didn't get any catharsis from doing so.

A very touching and thought provoking read.