



Newsletter - November 2011  
Cambridge M.E. Support Group



Hi everyone,

Well, that was Summer, that was. Now we're into the season of mists and mellow fruitfulness. Personally, Autumn is my favourite season. Still sunny and (hopefully) not too rainy, but cooler, with magical mists in the morning, and the astonishing variety of colours the trees turn. Sorry if I seem to be waxing a little lyrical, I went on a painting holiday in September! This, being the last newsletter of the year, is a little longer than usual, to give you something to read over the Christmas break. As ever, I do appreciate your feedback, so, if you can, please email me at [emma@rocketmail.com](mailto:emma@rocketmail.com) with any comments, suggestions, requests or contributions you may have.

**Next Meeting**

16 November 2011 – 7pm to 9pm at St Philip's School. A social meeting combined with making Christmas cards. If you don't celebrate Christmas, there will be the chance to make other greeting cards. We will supply materials, but **please bring your own scissors and something to lean on** (e.g. large hardback book or file). This is the last meeting of 2011.

Meetings are held at **St Philip's CE (A) Community Primary School, 2 Vinery Way, Cambridge CB1 3DR**. Everyone is welcome – families, children, friends & carers. The Library, including Group & Clinic Information Leaflets, will be at meetings. **Please don't attend meetings if you think you may have an infection as some of our members have weak immune systems.** A lot of our members have Multiple Chemical Sensitivities so please try to avoid wearing hair spray, body spray, perfume, or any strong smelling scents at meetings. For more information please visit [www.mcs-aware.org](http://www.mcs-aware.org)

**Future meetings**

Our meetings are generally held on the third Wednesday of the month.

Future dates for your diary - 18th January 2012 and 21st March 2012.

18 January 2012 – Bring and buy in aid of CMESG/liME. Bring all those unwanted Christmas presents!

**September Meeting Report – AGM and Cambridgeshire ME Service Talk**

Jill Down

The CMESG AGM took place on 21<sup>st</sup> September 2011 at the new venue, St Philip's School, at 7pm.

The AGM was quite a lively affair with a great turnout of 19 members including some new faces. It was held in the new venue at St Philip's school and it was a joy for us all to be able to park on site. Our thanks to Jayne for obtaining free access to this facility for our future meetings.

There was one resignation from the committee: Jill Down resigned due to caring and work commitments. The committee wishes to express its gratitude for all Jill's hard work over the years and to wish her well in the future – Ed.

Other committee members were re-elected to serve again with some taking on different roles: Rosemary Humby (Secretary); Rick Rickcord; Jo King (Treasurer); Emma Freeman (Newsletter editor); Gillian McLeish (Group Coordinator); Jayne Waldman. Our thanks and appreciation is extended to this group of people who manage to produce excellent meetings and newsletters, all whilst coping with M.E. or as carers of PWME.

New members were also elected onto the committee to ease the workload. A very warm welcome to: Bev Ralph (Library); Katharine Ward (Group Administrator - you may recognise her name as she has been sending out all the information emails to you over the last year); and Catherine Kennedy (Website Coordinator). Thanks, ladies! Welcome aboard!

The group then welcomed Dr Alex O'Reilly (GP with Special Interest) and Gill Watkins (Occupational Therapist) from the Cambridgeshire ME/CFS Service as speakers.

- They outlined the personnel in the service. 6 staff = 2.5 Whole Time Equivalent. This includes 3 part-time Occupational Therapists, an administrator and a nurse manager. Dr O'Reilly works 1 day a week with the service.
- They are based in Peterborough and do see some patients in Cambridge approximately every 8 weeks.
- They provide a service for people referred by their GP.
- They provide assistance with:
  - o a diagnosis, if one is required, and this is undertaken by Dr O'Reilly
  - o help with activity management/diary to identify patterns of activity – these often indicate a need to rest more, including reducing cognitive activity
  - o assistance to work with sleep patterns
  - o CBT techniques. They assured us they did not consider ME to be a psychiatric problem!
  - o General support via the telephone.
- They run some group sessions in Peterborough and do some home visits for severely affected patients.
- They normally see patients face to face 3 – 4 times and follow up by email.
- It is a small team who have had 1200 referrals in 5 years and patients are discharged when they have had no contact with the service for 12 months.
- The team has assisted with DLA and can write to employers if needed.

There was a general Q and A session and Dr O'Reilly spoke of some similarities in fibromyalgia and M.E. pain pathways. There was an opportunity for members to speak with the team over a cup of coffee more informally.

### **Subs**

Subs of £5 per year are due each September, so please send your 2010/11 subs to Mrs J King, CMESG, 62 Green End, Comberton, CB23 7DY. If you can, please switch to email newsletters, as this significantly reduces costs.

### **Meet the Committee**

We will be putting in a piece about one committee member each issue – a chance for those who can't attend meetings to put faces and stories to the names we read in our emails. This issue: Jill Down

This is my second year on the CMESG committee. We have a daughter who has had ME for 10 years and is severely affected and housebound. Five years ago we took the decision to try and set her up in her own home with carers, and four years later this became a reality after much anguish, help and support from the various agencies – it can be done! She continues to live in her own place and we all get by with help from carers. I am impressed daily with the dignity and fortitude she, and others like her, show when living with this illness. My desire is to see robust biomedical research into this illness so that people like my daughter, who are living in a vacuum, can access treatments and live life to their full potential. We also have a son who is married with three young children who live fairly locally, so our lives are rather extreme going from the quiet and stillness of one house, to another where the noise levels and activity are loud and boisterous. My time is pretty limited as I work full time so I am unable to attend many of the group meetings but I enjoy meeting you all when I do, and I have made some good friends by being on the committee.

### **Possible treatment breakthrough**

Further to comments made at and about the annual Invest in M.E. conference, you may have seen this on the news in October but just in case...

#### **Chronic fatigue syndrome eased by cancer drug**

An anti-cancer drug could hold the key to treating chronic fatigue syndrome (CFS). Symptoms of the disease eased in 10 of 15 patients given rituximab, an anti-lymphoma drug. Rituximab works by destroying white blood cells that make antibodies, called B cells. The results of the trial suggest that these white blood cells might be involved in causing CFS – a disorder also known as myalgic encephalomyelitis (ME), and one that has so far defied explanation.

The research was jointly led by Øystein Fluge and Olav Mella at the Haukeland University Hospital in Bergen, Norway. Their team discovered by accident that rituximab might work against CFS after seeing symptoms ease in a patient who had both lymphoma and CFS. "We think it affects all symptoms [of CFS], so it must touch the central pathological mechanism causing the disease," Fluge says.

Two of the 15 people in the trial appear to have completely recovered since they first received the drug three years ago. "Those two are both back at work," Mella says.

The researchers say that following two doses of the drug being given in the first two weeks of the trial, there was a lag of three to eight months before symptoms began to subside. They say this delayed response tallies with the idea that CFS is caused by autoantibodies – antibodies, made by B cells, that mistakenly attack the body's own tissues.

Rituximab is itself an antibody designed to target and destroy B cells. Mella says that all the B cells are gone within two weeks or so of the treatment, but autoantibodies typically survive in the body for another two or three months. "Washing out these antibodies is the most probable explanation for the time lag in benefits," he says.

Encouraged by the extended remission of two of the people in the trial, the Norwegian researchers are now checking whether further, periodic doses of rituximab could permanently keep the symptoms of CFS at bay. Mella says it is possible that the five who saw no benefits from the trial might have done so eventually if they had received further doses.

### **New biobank**

Rosemary Humby

Three charities – Action for M.E., the ME Association and ME Research UK – and a private donor have joined forces to fund the UK's first biobank of human blood samples for research into the causes of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (M.E./CFS). The biobank will be situated at London's Royal Free Hospital where it will be able to link in with the extensive research facilities at University College London. The full text of the press release, along with links to more detailed information, can be found at [www.meassociation.org.uk/?p=7540](http://www.meassociation.org.uk/?p=7540).

### **Invest in M.E. film showings**

Rosemary Humby

Invest in M.E. has arranged showings of *Voices from the Shadows* in London and Norwich. More information can be found at [www.investinme.org/Voices%20fromtheShadows.htm](http://www.investinme.org/Voices%20fromtheShadows.htm).

"Voices from the Shadows is a compassionate and moving exposé that bears witness to the tragic consequences of psychiatric prejudice and medical ignorance concerning one of the most prevalent illnesses of the 21st century. The film foregrounds the riveting stories of several British families confronting what must be everyone's worst nightmare: a loved one suffering a life-altering illness that leaves him or her bedridden and in constant pain, with no apparent cure. But what if the medical establishment made the situation worse instead of better? Such are the heartbreaking circumstances of the under-reported controversy surrounding ME (myalgic encephalomyelitis), aka chronic fatigue syndrome. Firsthand accounts from patients, caretakers, and medical experts paint a shockingly confused state of affairs—and underscore the urgency and frustration around this issue. A call to action for anyone who cares about the health and wellbeing of their community, this powerful film is equally a tribute to those whose voices must be heard."

Atissa Manshouri

Tickets for The Forum in Norwich on 2 December 2011 are £7 and tickets for The British Library in London on 7 December 2011 are £14 and can be purchased online via the website. Tickets are not refundable and wheelchair access can be arranged by ringing (0)20 7412 5528 / 5522.

### **Action for M.E. information and appeals**

Em Freeman

Action for M.E. is looking for people who have used Neuro-Linguistic Programming to try and manage their symptoms. Have you any advice or tips on its success, or otherwise? They would like to hear your experience, good or bad, for articles in forthcoming issues of *InterAction*, their quarterly members' magazine.

Action for M.E. is also looking for information on food additives and chemicals. Have you seen your symptoms improve after cutting out toxins e.g. additives in food or chemicals in cosmetics or household cleaning products? If so, and if you'd be happy to talk about it, please email them at [press@actionforme.org.uk](mailto:press@actionforme.org.uk).

Action for M.E. has set up a discussion forum called M.E. Friends online. If you fancy a chat, go to [www.actionforme.org.uk/get-involved/join-a-discussion-forum/me-friends-online](http://www.actionforme.org.uk/get-involved/join-a-discussion-forum/me-friends-online).

International Carers' Rights Day this year falls on 2 December 2011. If you have a carer, official or unofficial family member, you may wish to get involved in this awareness and gratitude day, see Carers UK: [www.carersuk.org](http://www.carersuk.org).

### **M.E. on the internet**

Em Freeman

This is an article by Toni Bernhard on the positive side of being housebound. It also contains a link to her blog, Turning Straw into Gold, and her book 'How to be Sick – A Buddhist-inspired guide for the chronically ill and their caregivers'. Toni was a law professor before she contracted M.E. and is an erudite and interesting writer.

[www.psychologytoday.com/blog/turning-straw-gold/201108/top-10-reasons-i-don-t-mind-being-housebound](http://www.psychologytoday.com/blog/turning-straw-gold/201108/top-10-reasons-i-don-t-mind-being-housebound)

As an aside, Psychology Today in September focused on humour as a possible health cure.

[www.psychologytoday.com/collections/201109/in-stitches-the-laughing-cure](http://www.psychologytoday.com/collections/201109/in-stitches-the-laughing-cure).

The International M.E. Association conducted an online survey in September about current treatments being used, in which we asked you to participate. The results and responses can be found at <http://mehealthquest.blogspot.com>.

There is an e-petition asking for biomedical research in the UK. If you would like to sign it, it can be found at <http://epetitions.direct.gov.uk/petitions/491> or via the Action for M.E. website. We have until February to get 100,000 signatures. There are currently fewer than 500. Please ask every family member and friend to also sign individually.

Deakin University in Australia is conducting research into chronic illness – ME, CFS, FM and Rheumatoid Arthritis. The full project title is 'Development of a reliable clinical and research assessment tool for Chronic Fatigue Syndrome and Fibromyalgia'. The first part of this process is a survey which tends towards the psychological, but this is only the first stage. Overall, there are cross-disciplinary papers, including a fascinating one looking at ME from a sociological point of view, particularly the successful self-empowerment of sufferers in the UK (vis the very existence of the All Party Parliamentary Group, etc). More information and the survey can be found at [www.deakin.edu.au/psychology/research/ci/](http://www.deakin.edu.au/psychology/research/ci/). Only over 18s can participate, I'm afraid. If you have any questions before you fill in the survey, please contact Emma Trifiletti at [eatr@deakin.edu.au](mailto:eatr@deakin.edu.au). Or you can ask me.

Your editor has recently discovered that a friend she has known for over 20 years did her PhD on cognitive impairment in CFS sufferers. Who knew?! There is a discussion at the outset of the various different definitions and criteria given to CFS and ME and PVFS. Throughout the paper, she uses the term CFS, but, to be fair, it was written in the nineties! Her experimental, observational and scientific conclusions, are that cognition is impaired in ME sufferers. We knew that, obviously, but it's nice to see it in print, without the usually-associated psychobabble. If you'd like to read the whole thing, I should warn you that, including bibliography, it is 272 pages long, but it's in big print, so you can take it slowly. It can be found at [http://etheses.whiterose.ac.uk/1393/1/uk\\_bl\\_ethos\\_251486.pdf](http://etheses.whiterose.ac.uk/1393/1/uk_bl_ethos_251486.pdf). Please note that, being rather long, it takes a while to load.

If you come across any M.E.-related sites, articles, surveys, research, blogs or merchandise, or if you have a favourite site you would like to share, please email me at [em-ma@rocketmail.com](mailto:em-ma@rocketmail.com).

### **MCS and EHS/ ES in the media**

Em Freeman

Multiple Chemical Sensitivity is a little known condition, which is often misunderstood as badly as M.E. itself. So I have been looking for positive mentions (or at least mentions) in the media that you may be interested in tracking down. If you have any other examples you would like to share, please let me know.

In the TV series 'Northern Exposure', the character Mike Monroe was portrayed as a hyper-allergic lawyer, called "The Bubble Man" at first. He moves to Alaska to escape the pollution that gave him multiple chemical sensitivity.

The 1995 film "Safe" was voted the best film of the 1990s in the 1999 Village Voice Film Poll. It tells the story of a woman's struggle to get diagnosed with MCS.

A BBC News article from 2006: [www.bbc.co.uk/insideout/east/series7/multiple\\_chemical\\_sensitivity.shtml](http://www.bbc.co.uk/insideout/east/series7/multiple_chemical_sensitivity.shtml)

Anne Lipscomb's 2009 memoir, Poisoned by Pollution: An Unexpected Spiritual Journey, details her struggle with MCS.

In an episode of the TV series "Bones", MCS patients are scammed and then murdered. Their MCS brings them together, but their illness is only incidental to the plot. It is taken as read that MCS is a serious medical condition with which every scientist in the team is fully familiar.

If you would like to learn more about MCS, a good place to start is at the Allergy UK website: [www.allergyuk.org/allergy\\_mcs.aspx](http://www.allergyuk.org/allergy_mcs.aspx) or [www.mcs-aware.org](http://www.mcs-aware.org). Other sites which might be of interest include Georgina Downs' UK Pesticides Campaign: [www.pesticidescampaign.co.uk](http://www.pesticidescampaign.co.uk), and the Pesticide Action Network: [www.pan-uk.org](http://www.pan-uk.org).

On 13 September 2011, the BBC News website ran a piece about a place in America where people with MCS and EHS (electromagnetic hypersensitivity) have moved to, in order to get away from the harm in their previous environments. It can be found at [www.bbc.co.uk/news/world-us-canada-14887428](http://www.bbc.co.uk/news/world-us-canada-14887428).

On 26 September 2011, the BBC wrote about an anti-magnetic cloaking device which is being developed in Spain, which sounds like a perfect fit for EHS sufferers. Unfortunately, everyone they interviewed fell over themselves to think of military applications, rather than medical ones.

If you are concerned that you may have EHS, first change your light bulbs. If you have modern, energy-saving lightbulbs in your living room, the first steps recommended are to stop using your remote control for your television (particularly if you have a Virgin box) and revert your lighting back to old-style lightbulbs, as the new ones are known to make some people feel ill. More information on this can be found at Migraine Action Association [www.migraine.org.uk](http://www.migraine.org.uk), and [www.migraine.com](http://www.migraine.com).

MCS Aware have a petition needing signatures by 18 November - [www.smartmeterpetition.org](http://www.smartmeterpetition.org).

### **Surviving Christmas**

Gillian McLeish

As usual at this time of year, we've put together a few ideas about getting through the Christmas period without getting too tired or stressed. To start with, why not come to the November meeting and have a go at making your own Christmas cards? If you're not well enough to get out, you can buy craft materials from [www.readicut.co.uk](http://www.readicut.co.uk) - or ready-made cards from [www.greetingscards.co.uk](http://www.greetingscards.co.uk). If writing cards is too exhausting or costly for you, you could always email a photo to close friends and family members, or send them an e-card - try [www.hallmarkcards.com.au/ecards/christmas](http://www.hallmarkcards.com.au/ecards/christmas) for cards with moving images and music or [www.foe.co.uk/living/cards.html](http://www.foe.co.uk/living/cards.html) for photographic cards.

If you are stuck for present ideas, why not ask your family for a wish-list of things they want or need? This makes finding presents much easier when you're brain foggy. If they're not wish-list types and you're having trouble thinking of anything, you could get a token gift (such as a novel or CD you know they'll enjoy or a box of their favourite chocolates) and some vouchers so they can choose something themselves. You can get vouchers online from shops such as Amazon, Lakeland Limited, John Lewis, and many others, or get National Garden Gift Vouchers via [www.nggv.co.uk](http://www.nggv.co.uk). You could also consider a subscription to a relevant magazine, or a gift membership of a charity - the RSPB, for instance, have membership categories for both children and adults: [www.rspb.org.uk/supporting/join/gift.aspx](http://www.rspb.org.uk/supporting/join/gift.aspx).

Don't forget when you are buying presents online that if you're registered with Everyclick you can raise money for Invest in ME by visiting stores via the Give As You Live section of their site: [www.giveasyoulive.com/search/stores](http://www.giveasyoulive.com/search/stores) - you don't pay any extra, and liME gets a donation whenever you shop via the links. If you're not registered, it's easy - just visit <http://fundraisers.everyclick.com> and click 'sign up' - when you're asked to choose a charity type in Invest in ME.

It's a good idea to plan a menu for the couple of weeks around Christmas, not just the day itself. This will mean you won't buy more than you need, won't forget anything, and won't have the stress of wondering what you're going to eat when you're too tired to think about it. Book your grocery delivery slot early so you can get things delivered at times which are convenient for you and don't have to face crowded shops. Remember you don't have to have turkey with all the trimmings just because it's traditional - you can choose your own, easier to prepare, treats. My Christmas dinner is usually smoked salmon, jacket potato, and French beans, followed by a baked apple - virtually no work except for coring and stuffing the apple!

If you're not well enough to see your family, perhaps you could talk to them via Skype, or make them a short video

message? If you are able to visit people, make sure they know in advance about any food intolerances you have, and that they are prepared for you to need a rest during the day - these things are much easier for other people to cope with if they're not unexpected.

Make sure you stock up on any medicines you're likely to need over Christmas, as well as things like vitamins - and if the weather is anything like last year's, hot water bottles and fluffy socks! If you're going to be on your own or you don't celebrate Christmas, make sure you have plenty of treats and interesting things to do, or arrange to phone a friend, so you don't feel too lonely. And don't forget, if you need to talk to someone, the Samaritans are always open - their number is at the end of the newsletter.

### **M.E. Hobbies – Gardening Help**

Gillian McLeish and Jo King

If you're a keen gardener but unable to do the things you used to do, you might find [www.carryongardening.org.uk/default.aspx](http://www.carryongardening.org.uk/default.aspx) helpful. It's a site for disabled and older gardeners, and gives advice about things like gardening from a wheelchair or finding tools suitable for weak muscles, though it's not really aimed at people with M.E. so it does assume a level of energy you might not have. [www.fredshed.co.uk](http://www.fredshed.co.uk) also gives advice about tools suitable for disabled users - email Fred if you need more personal advice than is available on the site. Finally, if you need help re-organising your garden to make it more accessible or lower maintenance, you could try applying for a grant from the Gardening for Disabled Trust via [www.gardeningfordisabledtrust.org.uk](http://www.gardeningfordisabledtrust.org.uk).

**Green Fingers 01223 458205** - Green Fingers is a gardening service available to those individuals who are infirm and/or disabled, in receipt of certain benefits, and have no-one who can help with their garden. If eligible you can receive assistance with grass cutting, pruning and weeding.

**Richmond Fellowship (ReFresh project)** - [tim.fear@richmondfellowship.org.uk](mailto:tim.fear@richmondfellowship.org.uk) Tel: **01223 301032** - Thanks to a recent Big Lottery grant award, this service now also runs a garden maintenance project called ReFresh. The project offers a heavily subsidised gardening service to elderly, disabled and vulnerable people to improve their environment.

### **Assuaging the spending urge**

Em Freeman

This website brings together artists who make Art Cards, which are small pieces of art, about postcard size. Prices start at around £1.75, which should fit most budgets. [www.art-cards.org/gallery/gallery2/main.php](http://www.art-cards.org/gallery/gallery2/main.php). Or you can have a go, yourself.

### **Eating out with a limited diet**

Em Freeman

When you can muster the energy for an evening out, it's worse than awful to find the menu full of things you can't eat. Here are a few places that cater for special diets and requirements.

**Rainbow Cafe, Cambridge** - Popular licensed vegetarian cafe in city centre, offers a range of vegetarian and vegan options. Free organic baby food. Organic beers and ciders.

**Chequers Inn, Eynesbury** - Child friendly pub and restaurant in St Neots with a classic a la carte menu and daily specials board. Gluten free and low carb diets catered for.

**Imperial Bento, Peterborough** - Contemporary Chinese restaurant with an a la carte buffet menu. Special diets catered for.

**Cinta Chinese Restaurant, Godmanchester** - Provides authentic, high quality cuisine. Special diets catered for.

If you have a favourite restaurant that caters for special diets, please let me know and I'll add them to the list.

### **Food Delivery at Home**

Wiltshire Farm Foods is the UK's leading frozen meal delivery service. They have Cambridgeshire County Council approval. Prices range from £2 and they deliver free of charge. They cater for all dietary needs, including pureed meals for those with swallowing difficulties, as well as diabetic and gluten-free. [www.wiltshirefarmfoods.com](http://www.wiltshirefarmfoods.com). Call them direct for a free brochure: 01476 571582, or contact them via Cambs. Adult Social Care on 0345 045 5202.

Daily Bread Co-operative has two branches, in Cambridge and Northampton. They deliver wholefoods and special dietary products, including quinoa for Rick's recipe. They sell organic and Fairtrade products. [www.dailybread.co.uk](http://www.dailybread.co.uk)

[www.goingorganic.co.uk](http://www.goingorganic.co.uk) deliver veg boxes to anywhere in the UK. Prices start at £13.50, and for a little extra, they'll add fresh seasonal fruit as well. All the produce supplied is certified organic and is free from additives, chemical fertilisers, pesticides and genetically modified organisms.

Rainbow Wholefoods, based in Norwich, also deliver. All their products are 100% vegetarian and GM-free. They stock gluten-free, Fairtrade, macrobiotic, sugar-free, salt-free and dairy-free products [www.rainbowwholefoods.co.uk](http://www.rainbowwholefoods.co.uk)

### **ME Hobbies – Blogging**

Gillian McLeish

Writing an online journal (web log, or "blog") is a good hobby for people with M.E. as it requires very little energy, and you can do as much or as little as you like on any given day. Being able to write makes you feel that you can still do something creative, even if you've had to give up more energetic creative hobbies. Obviously it requires internet access, but you don't have to be very computer literate, as there are several sites which do all the difficult bits for you: just go to [www.blogger.com](http://www.blogger.com) or [www.wordpress.com](http://www.wordpress.com) and follow the instructions.

You will have to think of a name for your blog, which will depend on your topic. If you're using the blog to keep in touch with family and friends you are unable to visit, telling them your news and posting personal photos, you might wish to call it something like "Janeandfamily"; whereas if you're going to be writing about a subject of interest to you, it would be better to think of a title which will appeal to other people who are interested in the same subject, such as "patchworkcraft" or "wildlifeinthegarden". If the title you want is already taken, change it by adding a hyphen or changing the word order, e.g. "patchwork-craft" or "gardenwildlife".

You have the option of choosing to make your blog private (so no-one can read it but you - probably useful only while you are getting started); visible to readers you choose (good if it's a personal blog for your own family and friends); or public for anybody to read (this is usual and is the default). If you go for the latter you can choose to moderate comments, so you can weed out any undesirable ones. If you value your privacy, you may also want to think of a username which is different from your real name.

You will need to choose a template (layout) for your blog, but don't worry, you can always change this later. You can also change things like the font and the colours if you are a bit more computer literate.

If you find it difficult to proofread what you've written or to read other blogs, there is software which will read aloud to you: try [www.deskbot.com](http://www.deskbot.com) or [www.naturalreaders.com](http://www.naturalreaders.com) (but do make sure you visit the manufacturers' own sites and that your computer has an up-to-date virus checker before you download these or anything similar; some sites which claim to offer free downloads may contain viruses).

It's a good idea to post something on your blog fairly regularly if you want to attract readers - but there is no requirement to blog on any particular day or at any particular time, and no need to post more than a few words if you're feeling foggy. If you are blogging because you enjoy writing, and aren't concerned whether or not people read your blog, or are just giving personal updates for your family, there is no need to worry about regular posting.

If anyone would like further advice about starting a blog, please feel free to email Gillian or Em.

### **Other people's blogs**

Many people with M.E. write blogs, although some of them are very severely affected and only post occasionally. Some blog about their M.E., others about completely different subjects.

<a href="http://dreamsatstake.blogspot.com">http://dreamsatstake.blogspot.com</a>	Two surprisingly positive blogs about living with severe M.E.
<a href="http://www.greenwordsgrowing.com">www.greenwordsgrowing.com</a>	
<a href="http://niceguidelines.blogspot.com">http://niceguidelines.blogspot.com</a>	This is a site written by a Dr Speedy. It is well-researched and is a good update on medical papers past and present, and also includes some of the less helpful information put out in the world, by Dr Wessely and the like. This makes for a well-rounded argument.
<a href="http://letsdoitforme.blogspot.com">http://letsdoitforme.blogspot.com</a>	The blog updates for Let's Do It for M.E., the force behind the fundraising for the biomedical research centre project.

<a href="http://livingwithchronicfatiguesyndrome.wordpress.com">http://livingwithchronicfatiguesyndrome.wordpress.com</a>	This is the site written by a young Australian man who tries every treatment he can lay his hands on and reports on every possible advance made in great detail. Some of it is rather technical, but it's worth ploughing on.
<a href="http://beefburgersandme.blogspot.com">http://beefburgersandme.blogspot.com</a>	This is a relatively new blog started last year by a mother of two who has M.E. and fibromyalgia. Shelley is hilarious, and also contributes to M.E. Facebook groups.
<a href="http://treatingxmr.blogspot.com">http://treatingxmr.blogspot.com</a> <a href="http://treatingxmr.blogspot.com/2011/04/informal-family-survey.html">http://treatingxmr.blogspot.com/2011/04/informal-family-survey.html</a>	This is a blog about XMRV, written by a doctor who is herself XMRV-positive. Some of her posts are rather technical. She is doing an informal survey to find out which diseases run in the families of people with M.E., and she'd like to get as many people as possible involved. So please read this and contribute your history.
<a href="http://mehealthquest.blogspot.com">http://mehealthquest.blogspot.com</a>	Connected to the International M.E. Association
<a href="http://forums.phoenixrising.me/forum.php">http://forums.phoenixrising.me/forum.php</a>	Phoenix Rising is an enormous site full of information and debate, along with some very thought-provoking forum threads where you can chat with other sufferers.

That's about it from me, this year. Have a good Christmas and (a quiet) New Year and I'll see you in 2012.

Luv  
Em.

### **Contact Column**

If you want to get in touch with other members, please send your contact details to Em and we will publish them here and on the website. If you don't want your information online, let us know when you contact us. Please note that CMESG takes no responsibility for anyone who contacts you this way.

Mireille Depledge      01223 416326 (10am-6pm)  
 Bryony Smith            [brysmith3@hotmail.com](mailto:brysmith3@hotmail.com)  
 Deanna Wooton         please contact Jo King at [joandgeoffking@hotmail.co.uk](mailto:joandgeoffking@hotmail.co.uk) for Deanna's address

<b><u>Useful Numbers</u></b>			
Disability Cambridgeshire (Directions Plus)	01480 839192 (M-F 10am-4pm)		<a href="http://www.disability-cambridgeshire.org.uk">www.disability-cambridgeshire.org.uk</a>
Samaritans 08457 909090 Samaritans Local	01223 364455		<a href="http://www.samaritans.org">www.samaritans.org</a>
AYME helpline (young people)	08451 232389 (M-F 10am-2pm; Wed 6pm-9pm)		<a href="http://www.ayme.org.uk">www.ayme.org.uk</a>
Tymes Trust (young people)	01245 401080 (M-F 11am-1pm, 5pm-7pm)		<a href="http://www.tymestrust.org">www.tymestrust.org</a>
Action for M.E. helpline	08451 232314 (M-F 11am-1pm; Mon 6.30-8.30pm)		<a href="http://www.afme.org.uk">www.afme.org.uk</a>
ME Association helpline (for non-members)	08712 227824 (10am-12pm; 2pm-4pm; 7pm-9pm)		<a href="http://www.meassociation.org.uk">www.meassociation.org.uk</a>
25% M.E. Group (severely affected)	01292 318611		<a href="http://www.25megroup.org">www.25megroup.org</a>
<b><u>Cambridge Group Committee Members</u></b>			
Co-ordinator	Gillian McLeish		<a href="mailto:gamcleish@yahoo.co.uk">gamcleish@yahoo.co.uk</a>
Secretary and Parent Rep.	Rosemary Humby	01223 842632	(no calls after 9pm) <a href="mailto:rosemaryhumby@aol.com">rosemaryhumby@aol.com</a>
Treasurer	Jo King		<a href="mailto:joandgeoffking@hotmail.co.uk">joandgeoffking@hotmail.co.uk</a>
Newsletter	Em Freeman		<a href="mailto:em-ma@rocketmail.com">em-ma@rocketmail.com</a>
Administrator	Katharine Warner	07799 691771	<a href="mailto:katharine.cmesg@gmail.com">katharine.cmesg@gmail.com</a>
Library	Beverley Ralph	07595315929	<a href="mailto:bev_ralph@hotmail.co.uk">bev_ralph@hotmail.co.uk</a>
Web contact	Catherine Kennedy		<a href="mailto:kittycatk@tiscali.co.uk">kittycatk@tiscali.co.uk</a>
	Jayne Waldman		<a href="mailto:jayne.waldman@ntlworld.com">jayne.waldman@ntlworld.com</a>
	Rick Rickcord		
Webmaster	Charlotte Kempin		<a href="mailto:charlotte@cam-me.org.uk">charlotte@cam-me.org.uk</a>
We are happy to hear from you, but PLEASE be considerate, especially if you need to phone someone. The committee members are all volunteers who have other commitments, personal problems, and some have M.E. too! Remember to visit our website & forum: <a href="http://www.cam-me.org.uk">www.cam-me.org.uk</a> . We welcome your contributions!			

### **Disclaimer**

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