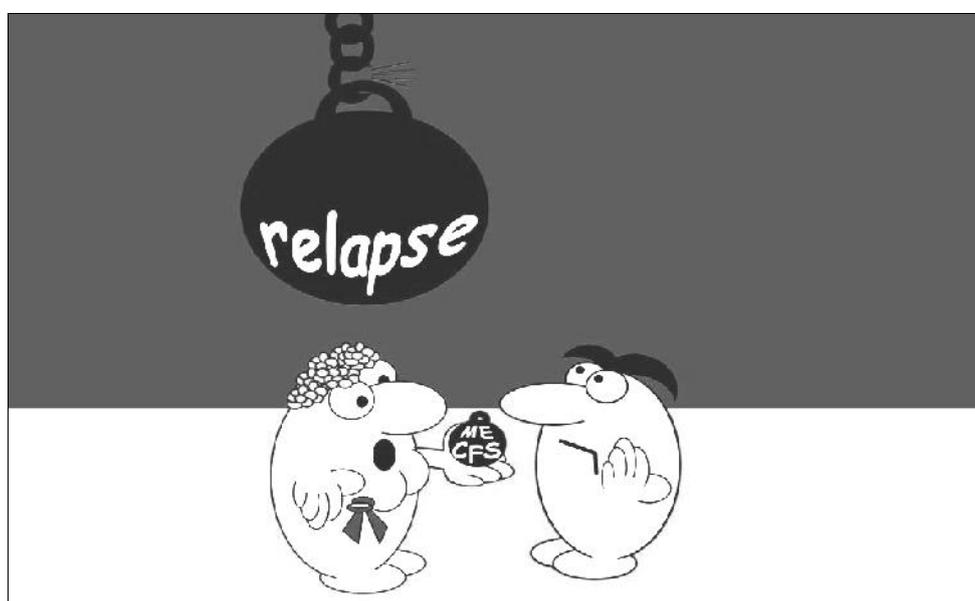


Welcome to Our October 2011 Newsletter



I think, I finally have CFS under control!

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.

Support Group Posts & Contact Information:

Group Contact / Welfare & Benefits Advice:	Pam Turner	
Treasurer & Parents' Contact:	Kim Finney	01204 882826
Minutes Secretary:	Margaret Benn	0161 761 2723
Bolton CVS Contact:	Ann Richards	01204 521769
Meetings Secretary:	Maria Sale	01204 575613
Medical Sub-Group, Group Rep & Carers' Contact:	Yvonne Leech	0161 764 7822
Bury Socials:	Sheila Myerscough	0161 7970026 (after 12noon)
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Supported by:
Health for Bolton, 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 20th October – Sara Grimshaw (Kirkman), Occupational Therapist with our clinic, will talk about ways of making life easier.

Thursday 17th November – Dr Carolyn Chew-Graham, The Head of the Manchester Research Team will be joining us so she can chat and mingle with us informally during our pre-Christmas social with “Bring & Share” buffet supper.

Please note there will be no meeting in December.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 7th November 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!**

Bury Socials: These are continuing on the first Thursday of every month, the next will be **Thursday 3rd November, 3pm at The Automatic, next to the Met theatre** (it is across the street from Yates, not the Met Café next to Yates), **Derby Hall, Market Street, Bury, BL9 0BW.** http://themet.biz/location/find_the_met.pdf. If you need any more information, please phone Sheila on 0161 7970026 after 12noon

Yoga Classes: Are **3:15pm-4:15pm 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.

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

Calling all Carers, a Help Request from Manchester University

Manchester University Research Team has asked for our help. They would like to be able to interview some of our carers for their research. If anyone is willing to be interviewed please can you contact Pam Turner and she will pass on your details.

Bury/Bolton ME/CFS Support Group Meeting

September 2011. by Pam Turner

For our September meeting we were very fortunate to have Don Stenhouse who has been curator of Natural Science at Bolton Museum for a number of years.

His remit is to look after all the natural history items and this now covers a multitude of different species including entomology, plants, molluscs, animals, birds and geology items such as rocks and fossils

In the past Don has worked in many places in jobs including being a bin man and washing up, but now he has a job that he loves, I'm sure after much necessary hard work, research and dedication.

Don explained that his role now includes a lot of educational work such as working on displays and events for children and families, such as:

- Worm Whispering – with a group of children Don digs holes and then extracts the worms so that the children can look at the hole and what kind of soil the worm lives in, before putting back the worms. Of course the children love digging and getting dirty.
- Bug Hunts – The children are given a small, expandable mesh bag in which to put the bugs that they find such as ladybirds etc, which Don identifies for them and then they are released. Inevitably some of the children would like to take them home as pets but are usually happy to return them when Don explains why it is necessary.
- Bat Nights – these are often family events and may be as many as 50 people will turn up. Don has special very strong beam torches which detect the bats in flight and also has bat detectors that pick up the ultrasonic sounds that bats make. He made us laugh when he told us that he has had many torches accidentally beamed into his face when a child turns to ask him a question.



Don also works with students who are doing research for their degree or masters and he showed us several thesis papers given to him by students having completed their qualifications with his help. His specialism is beetles and he can help to identify specimens for research involving the variety of such species in certain areas. He said that he works with people from 3 to 90.

The star of the evening was the most enormous cockroach I have ever seen. I know that my horrified expression every time it moved caused much hilarity, but one member was brave enough to hold it. It must have been four or five inches long and several inches wide but Don assured us it was a very clean insect and it likes to eat lettuce and cucumber.



The next object, he passed round was a small stuffed gecko, which is a type of lizard. He then passed round a stuffed starling which looked rather sad, then some cases of stuffed bats. These were over 100 years old because it is now illegal to harm a bat.

Then there was a case with specimens of 3 different moths in all stages of their life cycle from caterpillar, pupa and cocoon to moth.

My favourite was the display of large beautifully coloured South American butterflies. Some of them looked to be a gorgeous electric blue in colour but Don said that they actually have clear scales which when the light hits them at an angle, give the optical illusion of being this bright blue. The colour helps with camouflage and possibly to attract a mate.

Then there were tiny humming birds which also have beautiful colours in their tail feathers. The birds are no longer stuffed but are stored in polythene bags which are called skins because they are just that, the birds skins. These birds had helped a study being done of hat making in the 19th Century when feathers were extensively used and some birds became extinct.

Picture 1: Stuffed Tokay Gecko, Picture 2: Stuffed Bats Top Noctule, Left Pipistrelle , Right Long eared bat.

Bury/Bolton ME/CFS Support Group Meeting

September 2011. Continued...

Don also had molluscs (snails) and told us of a disastrous decision made in the Hawaiian Islands when a person imported African Land snails for food but the business failed, so they were let loose in the wild and decimated the vegetation. Against advice they then imported 13 different types of Carnivorous African snails to get rid of the original species but instead they ate the indigenous snails, which are now extinct. We now have some of the very rare specimens of the original Hawaiian snail population.



Don told us some funny stories about items he has been asked to identify such as a fossilised mouse which turned out to be a squeaky toy which had been buried in a garden, and a red beetle with yellow eyes which turned out to be a plastic toy.

Don said he enjoyed his job very much because it involves talking to people and having a laugh with visitors.

When asked where all the specimens came from Don said that very many of them were bought by the museum in 1911 from a collection built up by Philip Brookes Manson in the 1800's.



He didn't bring any animals because they are too big; specimens used to be brought in by the public and the museum employed a taxidermist to treat them but this is now too expensive and they have enough specimens anyway. The museum gave many birds and squirrels to Manchester University as they were doing research into bird skeletons.

We also saw part of a collection of very pretty and interesting stones, some with fossils.

Finally Don told us that there are over 60,000 plant specimens but pressed flowers are not good for display because they are fragile and lose their colour in the light. He told us that recently an artist came in to look at the collection in order to get inspiration. Don showed us a beautiful very large roll of lovely coloured panels made up of photographs of beetles and insects. It was probably 5 feet wide by about 6 feet long and it was made to hang in front of a window with natural light through it, to look like stained glass. This was also made by a student and was very impressive.



Another very interesting and enjoyable evening thanks to Don.

Picture 3: Extinct snails, Picture 4: Exotic Butterflies, Picture 5: Nemoralis Linn Darts, This is the mode for snails to breed.

John jumps for ME

In our April Newsletter you may remember that Paula Parrock's husband John was asking for people to sponsor him to do a parachute to raise money for Action for ME.

You will be glad to hear that John did his parachute jump and has received a letter of thanks from Action for ME as he raised £826, which Action for ME said "with little government funding and little recognition of ME your gift is worth so much more than pounds and pence".

Congratulations John on a job well done.

Panel of Experts Set New Criteria for the Disease, and Rename it to ME by Andrew Levy

On July 22 2011 a panel of experts published their views on Chronic Fatigue Syndrome/ME and how it should be diagnosed. Because of their findings, they also recommended a name change to just Myalgic Encephalomyelitis. The experts came from clinical practice, research, teaching and included a patient representative. Their final paper was checked and reviewed by their peers and none of them had a commercial or vested interest in the final results. Their aim was to collectively come up with a way of classing and diagnosing ME. To get agreement, they also used the Delphi Technique so that views of more outspoken people did not outweigh the opinions of quieter others. The panel believes that this new information, called the International Consensus Criteria, will help inform GPs and other health care providers, and will lead to better diagnosis, treatment and research.

To start with, the panel believes that ME patients are unable to properly regulate their central nervous and immune systems. They also believe there are problems with the way cells produce energy and with the heart/blood vessels. These issues lead to measurable differences in physical and mental performance, which can also lead to a deeper understanding of each patient's condition.

Having a better understanding of the origins, causes and symptoms of the disease, the team recommended a name change from Chronic Fatigue Syndrome to Myalgic Encephalomyelitis. By renaming it, this puts it into line with the classification by the World Health Organisation. To support the new name, the team pointed out that no other disease had fatigue in its name, even when fatigue was a symptom e.g. cancer/chronic fatigue or multiple sclerosis/chronic fatigue.

To support their findings, the panel also outlined some important flaws with previous attempts to categorise the disease. For example, they showed that the number of people with ME increased by 10 times when you moved from the Fukuda to the Reeves criteria. They also showed that people in the Reeves criteria could also be classed as having ME, but without having any physical symptoms. They also recommended that the 6 month period to wait for a diagnosis should be dropped. They felt that this was unfair on patients, and that clinicians should be able to provide a diagnosis once they are satisfied of the symptoms but irrespective of a time factor.

They felt the number one symptom of ME was post-exertional neuroimmune exhaustion (PENE). This means that after doing some activity exhaustion is brought on because of issues with the aspects of the nervous system directly affecting the immune system. They also clarified this by saying that the body simply couldn't produce enough "energy on demand" for that task. A person in this category would show any of the following characteristics: flulike symptoms, a rapid increase in physical and/or mental fatigue, exhaustion which may be delayed, a very slow recovery with the possibility of a relapse and a low threshold to becoming fatigued.

In addition they noted that the symptoms could start from mild (a 50% fall in activity level before illness) and work upward. The next grade was moderate (mostly housebound), severe (mostly bedridden) and very severe (totally bedridden and need help with basic functions). They also recognised the disease could change from day to day and hour to hour. It could also be very different in people who paced their activity compared to people who did not. Similarly they recognised that the effects would apply in different ways to different people. For example, an outstanding athlete could have 50% reduction in their pre-illness activity level but will still be more active than a sedentary person.

In order to be diagnosed with ME, the patient should also have at least one symptom from the 4 symptom categories:

Neurocognitive impairments: difficulty processing information, short-term memory loss

Pain: headaches, significant pain in muscles joints, tendons, abdomen or chest

Sleep disturbance: disturbed sleep patterns, unrefreshed sleep

Neurosensory and perceptual and motor disturbances: e.g. inability to focus vision, sensitivity to light or noise, muscle weakness, twitching, poor coordination, mental ability becomes more pronounced with fatigue

Panel of Experts Set New Criteria for the Disease, and Rename it to ME. Continued...

The patient should also have at least one symptom from the following five symptom categories in an area called Immune, Gastro-intestinal & Genitourinary Impairments.

Flu like symptoms which may be activated or worsened with exertion

Susceptibility to viral infections with a longer recovery periods

Problems associated with the gastro-intestinal tract e.g. irritable bowel syndrome

Genitourinary problems e.g. an increase in the urgency or frequency to urinate

Sensitivities to food, medications, odours or chemicals

Patients must also have at least one symptom under the category called Energy Production/Transportation Impairments.

Cardiovascular: e.g. inability to tolerate an upright position, light-headedness/dizziness

Respiratory: e.g. laboured breathing or a hunger for air

Loss of thermostatic stability: e.g. below normal body temperature, sweating episodes

Unable to cope with extremes of temperature

The team also dealt with differences in children, saying it may develop more slowly than in teenagers or adults. They also observed the most prominent symptoms were associated with the nervous system e.g. headaches, problems thinking properly and sleep disturbances. The headaches could be severe possibly leading to a rapid drop in temperature, shaking, vomiting, diarrhoea and severe weakness. Issues associated with thinking, called neurocognitive impairments, could be difficulty in focusing the eyes for reading or becoming dyslexic when fatigued. If a young person has ME they will not be able to undertake a full school programme.

In conclusion, the International Consensus Criteria provides a framework for the diagnosis of ME supported by a large amount of research and clinical experience. They believe the range of symptoms interact dynamically because they are “causally connected”.

In the future the panel are developing a scale so that the severity can be properly measured. They're also creating guidelines for physicians covering diagnosis and the subsequent treatments. They recommend that people meeting the International Consensus Criteria should be classed as having ME and removed from the Reeves empirical criteria and the U.K.'s National Institute for Clinical Excellence for Chronic Fatigue Syndrome. The benefits of having patients re-assessed and re-diagnosed should help researchers work with better sample groups, and be able to produce better quality research.

Bury/Bolton ME/CFS Service Update September 2011:

At our recent meeting with our ME/CFS Clinic team we were reassured that, despite the changes that have been happening, they are committed to giving us an excellent service, as usual. Dr. Gaber has been doing more sessions and will continue to do so whilst the other 3 therapists will still be running their usual sessions. New patients need to be referred to the Service by their G.P.

Existing patients, if they are encountering problems, may self refer back to the service by phoning the Clinic, for up to 12 months after their course of therapy has been completed. After that time they may be re-referred by contacting their G.P. This applies to both Bolton and Bury patients. At present all patients are seen at the Bolton Brightmet Clinic, except for extremely severe cases, where home visits may be arranged.

Advice on transferring from Incapacity Benefit to Employment Support Allowance. By Pam Turner

A member telephoned to tell me of the distress caused by a simple error. She had completed the form sent to her and had enclosed original letters of supporting medical evidence, as requested, and returned it in good time by registered mail. However she heard nothing for quite a while and was then informed that she would need to have yet another medical. She then tried to track down her original form and letters, which turned into a nightmare of being given many different numbers to call and automated replies. During her many conversations trying to track her form and letters she was told that she would have to send more originals because they don't accept photocopies. This was most distressing as of course she had sent the originals with the form. NB when sending medical supporting evidence, if you make an appointment at the Job Centre they will sign, date, and verify your photocopy letters to send with your form, so you can keep the originals. Of course you have to take in the originals and proof of your identity for them to see. You can then keep the originals in case of mishaps. Eventually she was given the correct number: 0800 2888 777 where you can track the progress of registered mail and found that it had been received the day after she had sent it, but it had not been noted on her file. All was well and eventually she was simply transferred onto the support group. Being in the support group does however mean that she can be contacted again in 6, 12, or 18 months time for review.

The Sebastian Coe health club at the Ramada Jarvis, Blackrod

has kindly agreed that our members can use the swimming pool, etc. for £3.50 per visit, and accompanying carers will pay the same (there won't be any charge if they don't use the facilities). The usual price is £8. There are woggles* available on request. Please contact Bernie Bateman (07932185945 by text please) or Maria Sale (01204 575 613 or maria113@talktalk.net) to add your name to the list if you haven't already done so. Then just make yourself known at the pool reception: no need for membership cards.

The pool is small, quiet and warm, and the changing rooms are very close, with a good disabled changing room. The manager, Mike Caldwell, is very empathetic, as he hired a member of staff who had ME and worked to build up his hours of working as he recovered.

Anyone who feels able to commit to a contract would pay £150 annually, and if they suffer a for a couple of months, say, would be able to tack that time onto the end of the contract at no extra charge (see the manager Mike Caldwell for details).

Mike has also said that if member's who live in other areas wish to approach a health club he is happy to talk to the manager, and Bernie has said she will give some pointers, too.

Mike will also be contacting me to let us know when the quiet times are, so we can miss the busy times. We will inform you of these times in our next newsletter and also post it up on our web page.

*Woggles, I've learned, are long sections of rubber that are used in hydrotherapy to improve core stability.

CFS Research Foundation

The CFS Research Foundation has just taken a serious blow to their funding which is now affecting their research programme. They had to give back grant moneys when Dr Kerr withdrew from CFS/ME research even though the research is being continued by Prof Paul Kellan and his team whom have worked with Dr Kerr in the last study. For more information go to: http://www.cfsrf.org.uk/index.php?option=com_content&view=article&id=63&Itemid=62