

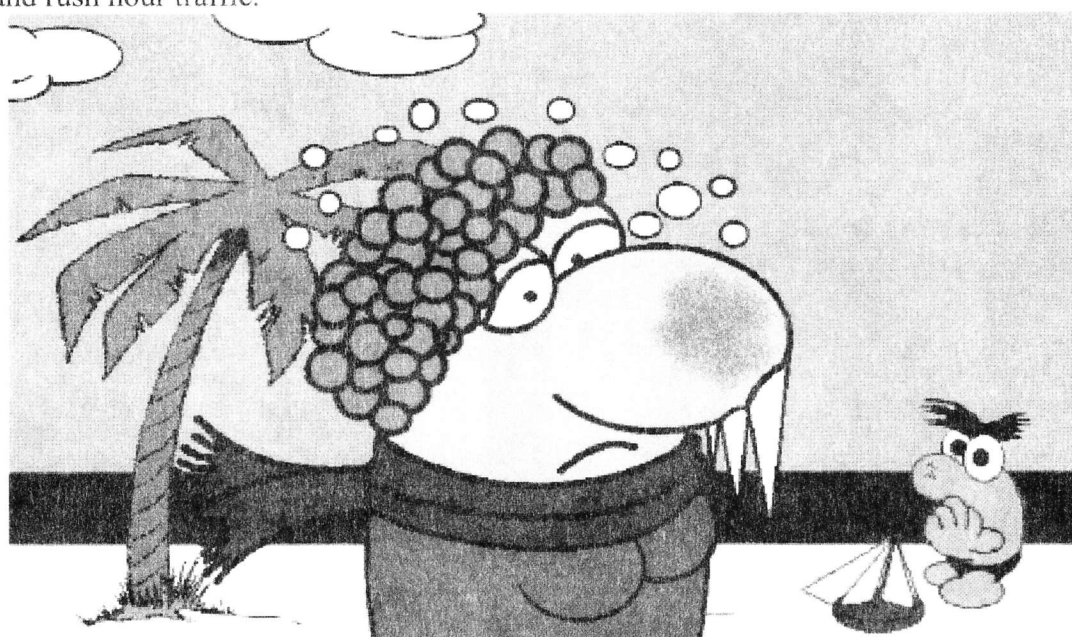
Welcome to Our August 2012 Newsletter

A Note from Alex: Well this month really does seem to be a bumper edition, as we have so much going on. You will find attached with this months newsletter a booking form for our next carers meals in January 2013 (so hurry up and book your place), an up to date Library list with a few new additions you may be interested in.

Please also note that we have a couple of new e-mail addresses in our Support Group Posts & Contacts Page.

Lastly we have decided to change the start time of our Radcliffe Social from 4pm to 2pm which will

take affect from September, as we hope this will help members from getting caught up in the school traffic and rush hour traffic.



Ever since she got CFS Emmy feels cold.

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, Alex Wootton, Carole Senior, Maria Sale, Lynda Marney & Phil Seddon

Support Group Posts & Contact Information:

Welfare & Benefits Advice:	Pam Turner	01204 793846
Treasurer	Lynda Marney	lynda@mesupportgroup.co.uk
Parents' Contact:	Kim Finney	01204 882826
Minutes Secretary:	Carole Senior	01942 810320
Bolton CVS Contact:	Ann Richards	01204 521769
Meetings Secretary:	Maria Sale	01204 575613
	maria@mesupportgroup.co.uk	
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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 September – Social with Alex selling her cards, (Alex has been busy making new cards for Christmas as she always has to be a few months ahead, other cards such as Birthday, Thank You and blank cards will also be available. With all of the profit from the sales going to our Support Group).

Thursday 18th October – Bridget Fox from BEST (Bury Employment Support and Training). It is an agency run by Bury council which can help people with disabilities to stay in work, but will also support and advise people not in work. Some of our members have used them for general advice and found them very helpful.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 3rd September at 2pm, 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.

Yoga Classes: Are 3:00pm-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.gmnneuro.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.

Please note that from September we have changed the time of our Radcliffe Socials at the Sparking Clog from 2pm till 4pm. We are hoping that this new time will mean that more of you may be able to attend, as hopefully this means that we will miss the school traffic and then the rush hour traffic.

Bury/Bolton ME/CFS Support Group Meeting

July 2012

For our July meeting, Phil Samphire from the Greater Manchester Coalition of Disabled People (GMCDP) came to give a very informative talk about their work and what they do.

The GMCDP campaign for the rights of disabled people by providing information and advice. Their Information & Advocacy Unit specialises in issues such as housing, benefits, rights, transport, and leisure activities. They produce a newsletter every 2 months or so.

They were established in 1985 and are a fully accessible organisation which only employs disabled people. Phil has been working there for eight years and his role is as a part-time information officer and as a project worker with young people.

One member asked Phil how to get a Blue Badge. The local council award these and if in Bury, you should call 0161 253 5151 and in Bolton, 01204 337266. You are automatically given one if you are in receipt of higher rate mobility Disability Living Allowance (DLA). If you are not, they will ask for your medical details and may write to your GP for more information to decide if you are eligible. You can also apply for a blue badge online at:

<http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/index.htm>

When asked how likely it was that someone with ME/CFS would get a badge, Phil said that if you can't walk more than 100 metres without stopping, you are probably eligible.

Phil told us about the schemes running in Greater Manchester to make travel cheaper for disabled people. The TfGM website has some helpful guides for disabled passengers:

http://www.tfgm.com/accessible_transport/

Transport for Greater Manchester (TfGM, formerly GMPTE) run a travel voucher and concession scheme.

Travel Vouchers aim to improve travel opportunities for people who cannot access buses. For every £1 you pay, it is worth £4 in travel vouchers to use in taxis, on Ring and Ride and Local Link, so you only pay a quarter of the fare. However, you can only buy £120 worth of vouchers a year at a cost of £30. So a journey worth £6 in vouchers will only have cost you £1.50. They are accepted by most taxi firms and they send you a booklet with a list of all participating firms. You can travel anywhere in Greater Manchester and the neighbouring counties. They are helpful for getting to hospital appointments where you know parking may be difficult. The scheme is open to those on higher rate mobility DLA or Attendance Allowance, and those who are registered blind, or cannot walk more than 100m or climb steps over 300mm (your doctor needs to verify this).

TfGM also run a **concessionary travel pass scheme** for free/concessionary travel on buses, trains and the Metrolink. Although you cannot have both the pass and the travel vouchers, only one of them, the Travel Voucher scheme card can be used for concessionary travel on rail journeys and Metrolink trams within Greater Manchester.

Some disabled people can travel for free on buses at all times in Greater Manchester using a **Concession Plus Pass**. This allows you to travel for free on buses at all times in Greater Manchester and for free on local buses elsewhere in England between 9.30am and 11pm Monday to Friday, and all day at weekends and on public holidays. You can also use your pass to travel for free, or for half the current standard fare before 9.30am, on trains and Metrolink trams. You may qualify for the Concession Plus Pass if you have severe walking difficulties, are blind or deaf or have been refused a driving licence for medical reasons. Contact Travel Concessions on 0161 244 1050 for more information

There was a discussion about whether scooters were allowed on trams, but the Metro website clearly states that they are not allowed on the Metrolink system, unless they are folded and fully encased. However, manual wheelchairs are allowed and stops are accessible by means of a lift or ramp.

The Metro platforms provide levels access for wheelchairs.

The Disabled Persons Railcard costs £20 a year, but entitles you to 1/3 off all fares for you and someone with you. If you get DLA, or are deaf or blind, you are eligible to apply. Call 0845 605 0525 or visit <http://www.disabledpersons-railcard.co.uk/>.

If you get a Railcard, as well as 1/3 off fares for you and your companion, Virgin trains won't charge more than £50 for any journey, no matter where you go or what time. Phil went to London during peak times for only £50 First Class, when tickets cost around £200! You can take your wheelchair or scooter on trains and Virgin should have at least 3 accessible spaces per train. Call the station before you travel to ask for help.

Phil's role as an information officer means he can share the hidden nuggets we all wish we'd known about sooner, such as the **Cinema Exhibitors' Association Card**. This card enables a carer (or friend, neighbour, etc) to a free ticket when you visit the cinema. This can be used at Cineworld, Vue, Apollo, Odeon, UCI cinemas and more

across the country, including art house cinemas. To apply for the card you will need to submit proof to show that you receive DLA/AA, or are registered blind. You can get an application form online or from cinemas participating in the scheme (unfortunately, they will not send out application forms by post). You will also need to supply a passport-sized photo with your application to appear on the card and a processing fee of £5.50 per card, which lasts for one year. To contact them, call 0845 123 1292 or visit <http://www.ceacard.co.uk/>.

The Royal Exchange Theatre offer half price tickets and The Lowry gives a carer a free ticket and 10% off, plus no booking fee and disabled parking facilities closer to the venue. However, you to get these offers, you must phone up their booking office direct, don't use ticket websites. Some tourist attractions, like zoos or theme parks, may also get concessions, so ask when you book tickets.

A member living in Rawtenstall told us about her struggle to get benefits, so Phil recommended the Community Care Helpline (0161 206 0283 from 9am-5pm) who will advocate on your behalf. They are based in Hope hospital, but will do home visits. They exist to offer ill/disabled people and their carers support, with such things as equipment, direct payments, care packages, hobbies, etc and are an extension of the Citizens Advice Bureau. Their website is: <http://www.adviceguide.org.uk>.

Shelter will also advocate for you (0344 515 1640), or Welfare Rights may also be able to help. Action for ME have a welfare rights helpline (for AfME members only). Don't forget our group also have access to a wide variety of Benefit and Work guides on claiming benefits! Pam stressed that it is important to send in as much supporting information as possible with the claim, such as letters from doctors, physiotherapists, social services, etc.

This lady also mentioned that she makes jewellery as a hobby and Phil suggested Full Circle Arts, who support disabled craft makers and artists by providing practical resources and services (visit <http://www.fullcirclearts.co.uk/>, or phone 0161 872 0326). She also wanted to get into education, so Phil advised her to look into Disabled Student Allowance or the Access to Learning Fund (<http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/index.htm>).

Phil stressed that the Coalition is all about disabled people coming together in self-organisation to fight against discrimination. He then explained the "social model of disability", which is when society doesn't take into account access needs:

Some disabled people's bodies work differently, or parts might be missing, which is an "impairment" and we live with this daily. This does not make us "less" than able-bodied people, but society thinks that there is something "wrong" with us.

A "disability" is when a disabled person is excluded from an activity because their needs are not taken into account. Phil used the example of a wheelchair user encountering a flight of stairs. Are they disabled because they use a wheelchair, or disabled because society has not taken into account their access needs? This also extends to things such as giving us extra time to complete tasks or getting information in Braille or audio form. These barriers exclude disabled people, but if society were to remove them by providing ramps, etc, we could be more independent as our needs have been met.

Phil said that schemes such as Access to Work exist to give us support in the workplace, such as voice recognition software or special chairs. It is important that we get the right support, as society is for everybody and we all have contributions to make. He emphasised that we are stronger in numbers and must come together to fight for the same thing.

Phil encouraged all of our members to get in touch if they need advice or information, you do not have to be a member. Phone 0161 273 5137, email info@gmcdp.com, or write to: GMCDP, BEVC, Aked Close, Ardwick, Manchester M12 4AN. www.gmcdp.com.

Carers Outing Update

We have been very fortunate that once again we have been awarded a grant of £800 for a carers outing. As you know, when we asked at our meeting where people would like to go the overwhelming response was The Red Hall. As £800 will only go so far to paying for the meal we have to ask you for a £5 contribution/person which will be non refundable.

We have booked the meal for Sunday lunch on 13th January, starting at 1 30pm. for 2pm.

If you would like to come please complete the menu selection form and send it with your contribution of £5 per person to Alex. **The cut off date for bookings will be 30th November** as we will have to let them know numbers and meal choices in advance and we can not be doing this over the Christmas period.

I do hope that as many of you as possible will come.

Please let us know if you have special dietary requirements. Also let us know if you have a preference as to whom you would like to sit on your table so that we can do a seating plan.

Your Committee.

Our Library by Carole Senior

As you probably know by now, we've had to move our library from it's cupboard in the church Hall. There are too many books for me to transport them all to our meetings, so I'll try to provide a broad selection each time but, if you want something specific, let me know and I'll bring it for you. An updated list of our books is enclosed with this newsletter.

We have 2 new titles to add:

- Patrick Holford – Improve Your digestion, (this book was recently reviewed and recommended by Tracy Morris. We have 2 copies, as one was kindly donated by Yvonne Leech).
- Elizabeth Turp – CFS/ME: Support for Family and Friends.

Many thanks to the vast majority of members who return books and CD's promptly (even if it needs a gentle reminder!) but, over the last year, we've had to replace nearly a dozen books, some of them Brand New. These were borrowed by people who then moved house and/or let their membership lapse, so that we were unable to contact them. There's still no time limit on loans, but please return items once you've finished with them so that others may use them. If you forget, I'm happy to call and remind you!

Lastly please note that I have a new E-mail address: caroles4@virginmedia.com

Hydrotherapy for Neurological Conditions

by Maria Sale

This pilot is being run at Bolton One and you don't have to live in Bolton to take part. Nor do you need to be water confident. The Physios that will run the course are Neuro-Specialists. There will be 2 courses consisting of 5 weeks, starting Wednesday 22nd August – 19th September, and 17th October – 14th November, 12pm – 2pm (each session will be 20 minutes). There will also be a small charge of around £5/session. There is no obligation, and there is also no guarantee we will be accepted on to the pilot. If you do put your name forward for this pilot you will receive a phone call from Lucy Aird one of the physios for a phone assessment.

If you are interested in this or you would like to know more please email or phone Maria Sale giving her your name and telephone number as soon as possible. E-mail: maria@mesupportgroup.co.uk or Tel: 01204 575613.

Would you like a Social in your Area? by Carole Senior

I understand that there's been some discussion of the following on our Facebook page and I apologise if I'm treading on anyone's toes but, for those like me who haven't been on there, would anyone be interested in meeting up in groups more local to them? I'd love to join in The Sparking Clog socials, but find Radcliffe just too much of a trek.

Time, place etc for any new groups would be up to those involved of course, so if you'd like a social group in your area, let me know and I can put you in touch with others near you. Ideas of venues would be good too – handy parking and easy access please.

I'm in Whesthoughton, but would be happy to help get things started in other areas. Please contact me by E-mail: caroles4@virginmedia.com or Tel: 01942 810320.

What's going on with our Local Health Services?

Yvonne and I were invited to be part of a group of Bury residents to comment on and inform the new Clinical Commissioning Groups, as they develop their plans during this next year. They are shadowing the Primary Care Trust and getting plans in place ready for the hand over next year.

The idea behind the changes is to ensure much greater local responsibility for the health care of the local community. **See the printed plan from Bury Third Sector Development Agency on the next page.**

At this first meeting we were only asked to comment on the wording of overall aims and plans, not the nitty gritty of the final content, to ensure it is in plain English and easily understood.

However, when we were told that they will be making their plans according to need and using the available data we asked "what about conditions like ME where there is no reliable data"?

The chairman was surprised at this but said he will ensure this is noted, and at the end of the meeting we made a new contact with a lady from Bury Public Health Department. "Since the meeting Yvonne has also raised this question of data with NHS Bury."

We are hoping that we can keep the profile of ME high so that we are included as a priority in the new Health Service model.

What is going on with our Local Health Services?

Commissioning Groups, Health and Well Being Boards, Patient Panels and Healthwatch – what do they all mean and what are they going to do? They are all creations of the new Health and Social Care Act 2012 and are in various stages of development, all will be fully functioning in April 2013.

Clinical Commissioning Groups

Clinical Commissioning Groups (CCG's) will take responsibility for the commissioning (designing and purchasing) of services.

Bury CCG is made up of all 33 GP Practices in Bury and its role will mean:

- *Engaging with local people to improve health and wellbeing*
- *Working with Bury Council and other partners to improve health and well being*
- *Ensuring that a wide range of health services are available*
- *Ensuring NHS monies are spent wisely*

Health and Well Being Boards

Each local authority has a health and well being board. Board members will collaborate to understand their local community's needs, agreed priorities and encourage commissioners to work in a more joined up way. They are a forum for key leaders from local health and care system to work together to improve the health and wellbeing of their local population and reduce health inequalities. They will have a variety of roles:

- *Developing a joint strategy for the Bury area*
- *Involving patients in decision making*
- *Influencing and informing local commissioning of health services*

They will have to involve local people in the development of the strategy for local health services.

Patient Panels

Patient Panels are part of the CCG (see left). They are made up of 12 representatives from across the borough. Members of the Patients' Cabinet will come together to represent the views of their local communities.

Healthwatch

Healthwatch will be the new consumer champion for both health and social care. It will exist in two distinct forms – local Healthwatch, at local level, and Healthwatch England at national level.

The aim of the local Healthwatch will be to give citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality. They will be separate organisation with their own board of trustees, but they will have statutory duties. They will have to work with patient groups, the CCG, community and voluntary groups and have a place on the Health and Well Being Board.

Joint Strategic Needs Assessment

And just when you thought it was safe to go back in the water – along comes the JSNA – Joint Strategic Needs Assessment.

Our interpretation of the JSNA is that it is the overarching primary evidence based on the factors that influence the health of a population including the social, environmental, and economic determinants of health. It is a statutory role for the CCG (see above) and the local authority to produce the assessment. The evidence is a crucial part of deciding what health services to commission.

Confused?

Well there is a lot that is changing and it will all need to bed in. The important thing is in the coming year there will be no doubt be many opportunities to be engaged in work of all the above. The whole of the third sector, big and small groups alike, have a crucial role to play in this change. B3SDA have, and continue to be involved in much of this development, the sector is there playing a part. If you want to be involved, contact us (Tel: 0161 797 1968 or E-mail: info@b3sda.org.uk), attend the Third Sector Assembly (next one being held on Thursday 6th September 2012) and Children, Young People and Families Groups' Forum, or register with us and get regular updates.

Whatever happens, we will continue to try and explain what's going on and help with the process of engagement.

This page has been reproduced from Bury Live, News from the third Sector in Bury July 2012 Edition 11.

A Low Cost Programme to Support People with ME/CFS/Fibromyalgia

A bit of everything to help with the vast range of symptoms by Barbara Heron

The Sustainable Health Partnership (a not-for-profit organisation) seeks to develop community provision for people with chronic long term conditions and to promote health in the community, schools and with individuals.

The increasing numbers of people who have a diagnosis of ME/CFS/Fibromyalgia indicate that it is now being more widely recognised by health professionals and treated seriously. However it remains true that for many people effective support is limited and hard to access. We work on the premise that ME/CFS and Fibromyalgia are a set of related conditions caused or affected by a number of factors including previous head injury, post-viral recovery, stresses in life, trauma and exposure to toxins. They affect everyone differently, are hugely disruptive and undermine the quality of life physically and emotionally.

Over the 20 years that we have supported people with this condition we know that there are many self-help strategies which can help both physically and emotionally. We have devised this pilot programme which is based on the Perrin technique of lymphatic drainage, but widened to include self-massage techniques, relaxation strategies, dealing with stress, support for anxiety and depression, nutrition, specific stretching exercises, some work on vision to reduce face and eye tension, individual and group support to exchange ideas and experience and to encourage a positive approach and ways of coping.

The next course will be in Prestwich, North Manchester, and will be held over 12 weeks, in sessions of around 3 hours. Each session will include a welcome and exchange of news, information giving and discussion, introduction and practice of a weekly activity to provide a personal toolkit to deal with individual manifestations of the condition. It will end with instruction and sharing of the Perrin technique and a review and question time. We will measure the effectiveness for individuals and will publish the overall results to GPs and health professionals to publicise the benefits of a personalised and holistic multifaceted approach.

If you would like to be involved or find out more please contact us: Barbara Heron Tel: 0161 798 5280 or Email: barbara@heronbg.info, Dennis Donnelly Tel: 077793 31860 or Email: info@alternativetherapynorthwest.com

Late Edition

Here's a brief roundup of some of the recent articles covering CFS/ME during July.

A new multicenter study published in The Open Pain Journal showed that daily consumption of the pentose carbohydrate D-ribose (Corvalen™: 5 grams, 3 times a day over 3 weeks) resulted in an average energy boost of 61% among patients diagnosed with CFS/ME and fibromyalgia. In addition, sleep, pain, mental clarity and overall well-being improved. **New Multicenter Study Shows D-Ribose Increases Energy 61% in CFS and Fibromyalgia Patients - healthcareglobal.com – 16 July 2012**

This interview with Dr Dan Peterson contains a number of updates on drug treatment and research into CFS. For example, it discusses the prospects for a new unlicensed drug called Ampligen, and the prospects of research into aspects of the immune system and linkages, for example, to cancer, viruses and other pathogens. **Dr Dan Patterson - Working to turn the tide for ME/CFS – prohealth.com – July 23, 2012**

Making a complete recovery from CFS can be difficult. In this study, 25 people with CFS lasting 25 years or more were analysed. Five of those people still had the disease, whilst the health of the other 20 was significantly less than a healthy sample of other people. **Even in 'Recovery,' Chronic Fatigue Syndrome Symptoms Persist – about.com – July 11 2012**

The story of Judy Mitkovitz is covered charting her journey researching chronic fatigue syndrome, and suggesting a link to the XMRV virus which other laboratories couldn't prove. Although the findings eventually had to be withdrawn, scientists such as Ian Lipkin are still looking at her theory to see if the results can be repeated. **How Research into Chronic Fatigue Syndrome Turned into an Ugly Fight – The Daily Beast – July 23, 2012**

27-year-old Michelle Penny describes what it's like living with ME and the effects on her family. The article also contains a useful summary describing diagnosis, treatment and links to more support. **Living with ME – WalesOnline.co.uk – July 28, 2012**

Sleep can be a problem for many sufferers, and with that in mind about.com are conducting a poll to see what sleep medications people take. Although it's not an article, it does contain links to aspects of sleep linked to CFS/ME. **Sleep Meds for Fibromyalgia & Chronic Fatigue Syndrome – about.com - July 27, 2012**