

# BURY/BOLTON ME/CFS SUPPORT GROUP



## Application Membership/Renewal Form

**The Bury/Bolton ME/CFS Support Group.** Membership fee minimum donation of £8.00 please

Your donation is important as it not only helps to run the group, it funds our campaign for awareness and medical provision.

Mr/Mrs/Miss/Ms/Other.....

Surname.....

First-Names.....

Address.....

.....Post Code.....

Telephone Number (including STD Code).....

EmailAddress.....

Date of Birth.....Partners/Carers Name/date of birth.....

Do you have ME/CFS.....Duration (months/years).....

Have you had a positive diagnosis? YES/NO

If YES please give details of who diagnosed you? Own GP/Hospital/Other.....

How did you hear about the Group? .....

I would like to receive newsletters via:  Email (saves us funds)  
 Post

I enclose the sum of £.....as a donation towards the work of the Bury/Bolton ME/CFS support Group for the benefit of people with ME/CFS and their carers.

Please make cheques payable to: **BURY/BOLTON ME/CFS SUPPORT GROUP** and send to:

**Kim Finney, Treasurer, Bury/Bolton ME/CFS Support Group  
Wits-End, 19 Hillstone Close, Greenmount, Bury, BL8 4EZ.**

Feel free to contact Pam (Group Contact) on 01204 793 846 if you need any further details.

Thank you.

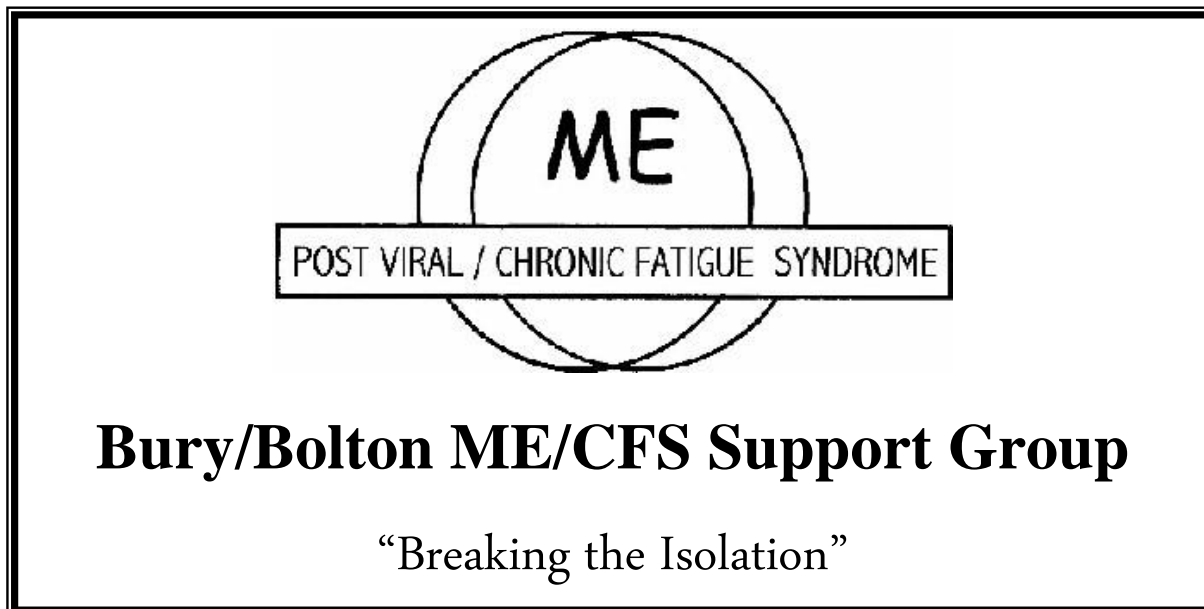
## Group Membership Survey

Thankyou for completing this survey. It will be most useful to have some statistics for people with ME/CFS in this area. This is also helpful when we are campaigning for local services and when we apply for funding grants. This information will be kept anonymous.

1	Are you sufferer or carer?	Sufferer		Carer	
2	Gender	Male		Female	
3	Age Group	Under 16			
		16-24			
		25-34			
		35-44			
		45-54			
		55-64			
		65 and over			
4	Ethnicity	White		Asian	
		Black		Chinese	
		Mixed Race		Other	
5	Please write the first part of your postcode (eg. BL3)				
6	Do you have access to transport?	Car driven by you.			
		Car driven by carer/friend.			
		Taxi			
		Public transport (train/bus/etc)			
		Other			
		None			
7	Are you employed or in education?	Yes		No	
		Full-Time		Part-Time	
8	Are you registered disabled?	Yes		No	
9	Are you receiving benefits?	Yes		No	
10	How long ago was your ME/CFS diagnosed?				
11	How long did you wait for a diagnosis?				
12	How severely affected are you?	Mild		Moderate	
		Severe		Very Severe	
13	Who gives you treatment?	GP		Both GP & Consultant	
		Consultant		Other	
14	How long have you been a member of the Bury/Bolton ME/CFS Support Group?				

With thanks to Central Lancs ME/CFS Support Group

**Please return this form along with your membership/renewal form.**



**Issue: 59**

**April 2011**

**[www.mesupportgroup.co.uk](http://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	01204 793846
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)
Web Master:	Caroline Higson	01204 525955 <b>caroline@mesupportgroup.co.uk</b>
Membership Secretary, Newsletters & Distribution:	David Gore	07919 234256 <b>Dave@mesupportgroup.co.uk</b>
Librarian:	Carole Senior	01942 810320 <b>carole.senior@tiscali.co.uk</b>
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 <b>andmk1@googlemail.co.uk</b>

**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.

**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.

**Don't forget, there is no meeting in April, the next will be Thursday 19<sup>th</sup> May.**

**19th May 2011, 7:30pm** – Jean Kay will do a session on card-making, providing materials for a couple of different types of cards

### **Radcliffe Socials: PLEASE NOTE CHANGE OF DATE DUE TO BANK HOLIDAY**

Our Social Group usually meets informally on the first Monday of each month, however due to the first Monday of May being a bank holiday, we are going to temporarily change to the second Monday.

Our next will be on **Monday 9<sup>th</sup> May at 4pm, at The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY.**

**In June we will be reverting back to our usual first Monday of the month.**

For more information please phone 07919 234256 or email [dave@mesupportgroup.co.uk](mailto: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 5<sup>th</sup> May, 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](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](mailto:olivia@oliviayoga.co.uk) for more information.

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

### **John jumps for ME**

Paula Parrock, a member of our support group, has had ME for 12 years. Although she has managed well, she had a serious relapse last October, which led to a 3 week stay in hospital. The relapse was so serious her husband John decided to play his part by doing a parachute jump in aid of Action for M.E. The charity is dedicated to improving the lives of people with M.E. and leads on campaigns for better treatment and research. They also provide information and support to people affected by M.E.

The jump will be on 22<sup>nd</sup> May, and both Paula and John would be very grateful if you could make a donation. If you want to support this worthy cause, please could you send a cheque payable to "Action for M.E." and post it to Paula Barrack, 155 Bolton Road, Kearsley, BOLTON, BL4 9BX.

PS: At the March support group meeting, Paula collected an impressive £85. She'd like to thank everyone who gave so generously.

## Membership Renewals 2011-2012

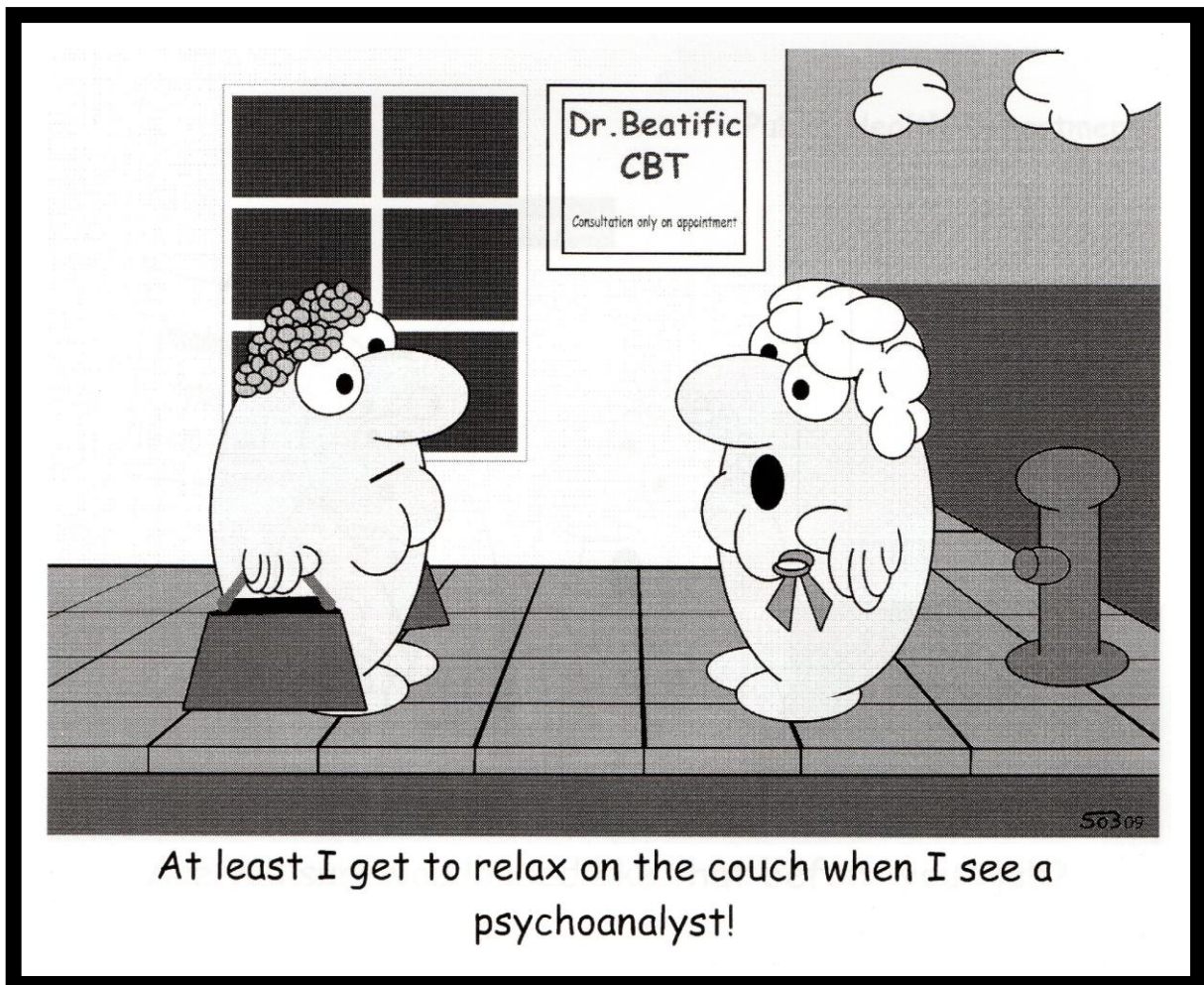
You will have probably already noticed the membership renewal form we have sent you with your newsletter – yes it's that time already again!

Just to remind anyone who isn't familiar, our membership year runs from April to April for everyone, however any new members who have joined us from December onward already have this year included and do not need to renew until April 2012.

For everyone else, if you wish to continue with your membership, please complete and return the forms along with your payment.

Don't forget, we no longer issue membership cards, but if you are unsure about when you joined or forget whether or not you have renewed, you can call Dave on 07919 234256 or email [Dave@mesupportgroup.co.uk](mailto:Dave@mesupportgroup.co.uk).

You will notice that the form is now two pages long as we have added a member survey; this is because when we are applying for grants for the group, we are often required to provide this demographic information.



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



## **Bolton/Bury ME Support Group Meeting March 2011**

Our March meeting was our AGM and I am really grateful to the 27 people who were able to attend and to those who sent apologies.

It was the shortest AGM on record taking just 20 minutes for the business to be concluded.

That left plenty of time for everyone to have one (or two) pieces of the delicious cakes on offer, thanks to members who brought some along.

One of our member's husband is going to do a 14000 foot parachute jump and hopes we will all try to sponsor him, proceeds going to ME Research UK. More details to follow.

Also I announced that we may have to change venues for our meetings as I was told that the Church were moving. However I am very happy to say some of the Church committee members were holding a meeting at the same time as us and have assured us that we will not have to move.

Thank you again to all who attended and hope to see as many of you as possible throughout the year.

## **Meeting at Manchester University 16 March 2011**

Pam and Yvonne attended a group meeting led by Prof Carolyn Chew-Graham, who is a GP as well as being Professor of Community Medicine at Manchester University.

The group have been awarded a grant, for Research for Patient Benefit, which is to be used to develop resources to enable GPs to diagnose ME accurately and to be able to support patients.

Discussion was held on practical issues such as available rooms for their base and the appointment of a research assistant.

Very important for us is the need for patient involvement and contribution of ideas. We have been asked to find volunteers who would be willing to attend meetings or to be interviewed in their own home if not well enough to attend meetings. I would be very pleased if people willing to help would phone me to let me know.

We also discussed a name for the project and Colette (one of the lead workers to contact GPs) supported us by stating that the name should include ME rather than CFS. At present it looks as though it will be called METRIPC = ME Training and Resources in Primary Care.

This is a wonderful opportunity and a really exciting time, please, please consider giving us your name as willing contacts. This is your chance to have your say in how services are provided.

# **Group Leaders Report AGM March 2011**

Once again I take the opportunity to say thank you to all the wonderful people who give their time and effort, to ensure that our group continues.

We owe a big vote of thanks to our treasurer Kim for balancing our books and ensuring that we stay within our budget and for preparing the books for the auditors. Thank you Kim.

Another big job is membership secretary and producing our newsletter, for this mammoth task our many thanks go to Dave.

Maria does a brilliant job of arranging our speakers and we have had a very interesting mix this year, all most enjoyable. Thank you Maria.

Once again we thank Caroline for keeping our excellent website updated, even though she is very busy studying. Thank you Caroline.

Yvonne has continued to attend many meetings on our behalf even though this has been the most distressing year for her and despite her own health problems. Thank you Yvonne.

Our thanks go to all our committee members for attending meetings and planning events and for arranging the socials at Radcliffe and Bury. A big thank you to all of you.

We also are very fortunate to have a lot of volunteers who each do different jobs for the group; Andy writes reports, Hilary does my typing and makes my job easier, Carole does a great job as librarian. Margaret is our minutes secretary at committee meetings. Pat is essential in her role as tea lady and Sue our meeter and greeter and door lady. Angela ensures our leaflets and posters get to all the libraries. It is really wonderful that we have so many people who give of their very limited energy. My gratitude goes out to all of you. Thank you so much for making my job manageable.

We are always grateful for anyone who feels they can help, in however small a way, so if you feel that you can offer some help we are always very grateful.

Our anniversary year has been most eventful and I believe very successful and I thank everyone who has helped to make it a good year for the group. Thank you to all our members for coming along to the meetings and for making new members welcome, it is much appreciated.

We will be having a change of venue in the course of the next year as the Methodist Church will be moving out of these premises. We have booked our meetings here until our pre Christmas party in December but after that we will have to find a new home. We will of course keep you updated on when and where the changes will occur.

Once again my thanks and love to all of you, committee, members, helpers; stronger together and caring for one another.

## **Secretary's Report 2011 AGM March 2011**

This year has again been both busy and enjoyable and although we have lost some members others have joined and our membership remains at around 164.

We have held our usual 9 meetings at Harwood, Longsight Methodist Church Hall and most have been well attended. Once again we have had interesting array of speakers, Charles Tulley was very informative telling us about the Alexander Technique; one of our favourites is Hugh Templeton and he didn't disappoint us and everyone had a lovely evening painting. Petra Barlow gave us an interesting insight to her experiences of holistic therapies. We had an absolutely fascinating evening listening to Dr Carolyn Routledge recalling her experiences in Egypt. Alistair Mirfin gave us some very valuable information about the Bury Carers Outreach Service and our last speaker was Emma King, a holistic therapist.

We also had two social evenings when we all enjoyed the cakes in June and the party food in November.

The big event of the year was of course our 20th anniversary meal at the Red Hall. It was a brilliant occasion for which we can thank Greater Manchester Community Foundation for their generous grant.

Our Yoga sessions have continued this year and we have a good regular attendance, apart from a few weeks when the snow disrupted things.

Our Socials at Radcliffe Sparking Clog on the first Monday of the month and at Bury on the first Thursday of the month have continued with various numbers attending.

We have been fortunate enough to have been able to have 3 carers outings for a pub lunch. The first one being a Christmas lunch held early in December, was a very successful event. The other two held in February at the Ainsworth Arms were also very much enjoyed.

We have attended meetings of the Clinical Network Co-ordinating Centre but were very disappointed to find out that in the re-organisation of the Health Service the CNCC will be managed under the Manchester Mental Health Trust. We have made our views known on this subject.

We have only attended one meeting of the local Multi Disciplinary Team for the ME service locally.

Yvonne continues to represent us at the National Framework for Long Term Neurological Conditions meetings in Bury. She also continues her links with Bury Carers



## **Retrospective ESA time limit for some people**

The DWP has confirmed that the proposed 12 month time limit to be imposed on people claiming contribution-based Employment and Support Allowance (ESA) will be applied retrospectively when it comes into force on 1 April 2012.

This means that anyone who starts receiving contribution-based ESA after that date will only be able to do so for 12 months and that claimants who have already been receiving contributory ESA for 12 months or more will have their payments stopped immediately.

The 13 week assessment phase will form part of the calculation of the 12 month period.

Where a person is transferred from Incapacity Benefit to contribution-based ESA, the 12 months will begin to run from the date of their transfer to ESA.

The 12 month time limit applies only to people in the work-related activity group for contribution-based ESA. It does not apply to claimants in the support group or to claimants who receive income-related ESA.

Action for M.E.'s Welfare Rights Adviser Sarah Lawrence says: "Other benefits that may be available after the time limit is up will vary depending on personal circumstances.

"Some people will be able to move onto income-related ESA as long as they have capital not exceeding £16,000, have a low enough household income, and their partner, spouse or civil partner does not work more than 24 hours per week and also has a low enough income.

"People with savings, other income or a partner, spouse or civil partner who is working are less likely to qualify.

"Other benefits that might be available after the 12 month time limit on contribution-based ESA include Job Seekers Allowance, Income Support on the grounds of being a lone parent or carer, Housing Benefit, Council Tax Benefit and/or Tax Credits. Entitlement will depend on a number of factors including capital, household income, whether they are in a relationship, whether they can do some work, have children etc.

"If anyone thinks they should be moved into the support group for ESA, they will either need to appeal if they are within the time limit or ask for the decision to be revised. This would usually be on the grounds that their condition has deteriorated since the original decision. I would suggest they seek proper welfare advice BEFORE as there is some risk attached."

If you need advice, contact our Welfare Rights Line (see p 8).

To add your concerns and suggestions to our campaign activity on this issue, contact Policy Officer Tris Rodriguez. Tel: 0117 930 1325 or email [tristana.rodriguez@actionforme.org.uk](mailto:tristana.rodriguez@actionforme.org.uk).

**From 'Interaction' Spring 2011, with thanks to Action For ME**

### **Reminders**

**Equipment Hire:** We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

**Amazon:** The group gets 5% commission when you shop at [www.amazon.co.uk](http://www.amazon.co.uk), but only if you follow the link from our own website [www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk).

## **SOME CONTACTS YOU MAY FIND USEFUL**

**Benefits Agency Information Officer:** Bolton - 01204 367000 Bury - 0161 762 2000  
**Bolton Primary Care Trust:** 01204 907724  
**Bury Primary Care Trust:** 0161 762 3100  
**Citizen's Advice Bureau:** Bury - 0161 761 5355 Bolton - 01204 900200 (/213 Housebound)  
**Disabled Living:** 0161 832 3678  
**DIAL** Disability Information and Advice Line: equipment/gadgets and where to get them: 0161 703 8887  
**Bolton Community Voluntary Services:** 01204 546010 **Carers Support (Bolton):** 01204 363056  
**Bury Council for Voluntary Services:** 0161 764 2161  
**Social Services:** Bolton 01204 337841  
Bury (town hall) – 0161 253 5000 (ask for adult social care team)  
**Bury Carer Services:** : 0161 763 4867 and **Bury Carer Assessment:** 0161 253 7190.  
**Basic Neurocare Centre (inc Assisted Gym):** 554 Eccles New Road, Salford, M5 2AL: 0161 707 6441  
**Ring & Ride:** Bolton - 01204 388500 Bury - 0161 764 1999  
**Welfare Rights Advice Line:** 01204 380460  
**Benefits Helpline:** 0800 882200. **Completing Forms:** 0800 44 11 44  
**Equality Human Rights Commission (was Disability Rights Commission):** 0845 604 6610  
**JOB CENTRE PLUS:** [http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled\\_People\\_and\\_Carers/index.html](http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled_People_and_Carers/index.html)  
**ACCESS to WORK:** [http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev\\_015798.xml.html](http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev_015798.xml.html)  
**General government guidance on entitlements:** <http://www.direct.gov.uk/DisabledPeople>  
**SHOPMOBILITY:** **Bolton** – 01204 392946 **Bury** – 0161 7649966  
**Manchester Arndale** - 0161 839 4060 **Trafford Centre:** 0161 749 1728  
**Bolton Market Place - Wheelchair Service:** 01204 361100  
**ACTION FOR ME:** 3rd floor, Canningford House, 38 Victoria Street, Bristol. BS1 6BY.  
Tel: 0845 1232380 (or 0117 9279551), e-mail [admin@afme.org.uk](mailto:admin@afme.org.uk) for general enquiries  
Welfare Rights Helpline – 0845 1228648 - Mon 9-5, Tues 9:30-12:30 & 3:15-6:45, Wed 1:30-4:30, Thurs 9:30-1:00  
Telephone support - 0845 1232314 (11am to 1pm Mon to Fri) - advice and information for anyone affected by ME (including non-members). [www.afme.org.uk](http://www.afme.org.uk) or for young people with ME [www.a4me.org.uk](http://www.a4me.org.uk)  
**ME ASSOCIATION,** 7 Apollo Office Court, Radclive Road, Gawcott, Bucks., MK18 4DF. 01280 818968.  
Information Line: 0870 444 1836 (10am to 12noon, 2pm-4pm & 7pm to 9pm – every day) [www.meassociation.org.uk/](http://www.meassociation.org.uk/)  
**BRAME:** (Blue Ribbon for the Awareness of ME) 30, Winner Avenue, Winterton on Sea, Great Yarmouth, Norfolk. NR29 4BA. Tel/Fax - 01493 393717. The BRAME campaign was launched to create a greater awareness and understanding that ME is a very real and debilitating illness. [www.brame.org](http://www.brame.org)  
**CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION:**  
2 The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. [www.cfsrf.com](http://www.cfsrf.com)  
**M.E. Research UK:** The Gateway, North Methven Street, Perth, PH1 5PP. 01738 451234 [www.meresearch.org.uk/](http://www.meresearch.org.uk/)  
**NATIONAL ME SUPPORT CENTRE:** Disabled Services Centre, Harold Wood Hospital, Romford, RM3 9AR.  
01708 378050 <http://www.nmec.org.uk>  
**The 25% ME GROUP:** Simon Lawrence, 4, Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ ME Group for the Severely Affected ME sufferer. [www.25megroup.org](http://www.25megroup.org)  
**CHROME:** (Case History Research on ME), 3 Britannia Road, London SW6 2HJ. 020 7736 3511 This charity was set up to identify as many severely affected ME sufferers as possible in the UK and monitor the course of their illness over 10 years. The study will supplement medical research into the condition.  
**TYMES TRUST** (The Young ME Sufferers Trust): P.O. Box 4347, Stock, Ingatestone, CM4 9TE, Advice line 0845 003 9002 (Mon-Fri 11-1 or 5pm-7pm). [www.tymestrust.org](http://www.tymestrust.org)  
**AYME:** Association for Young People with ME, Box 605, Milton Keynes MK2 2X. 08451 232389. [www.ayme.org.uk](http://www.ayme.org.uk)  
**INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS):** help with NHS complaints: 0845 120 3735  
**COMMUNITY LEGAL ADVICE:** 0845 3454345 [www.communitylegaladvice.org.uk](http://www.communitylegaladvice.org.uk)  
[www.writetothem.com](http://www.writetothem.com) - type in your postcode to find out who is your MP/MEP/councillor & how to contact them.  
**The Pensions Advisory Service (TPAS):** 0845 6012923 [www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)  
**The Pensions Ombudsman:** 020 7630 2200 [www.pensions-ombudsman.org.uk/](http://www.pensions-ombudsman.org.uk/)