

Issue: 41

October 2009

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)
Web Master:	Caroline Higson	01204 525955 caroline@mesupportgroup.co.uk
Membership Secretary, Newsletters & Distribution:	David Gore	0560 133 5037 Dave@mesupportgroup.co.uk
Link Up Co-ordinator:	Stephen Walker	01204 842395 stewalker@postmaster.co.uk
Librarian:	Carole Senior	01942 810320
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 andmk1@googlemail.com

DISCLAIMER:

The observations expressed in our newsletter may not necessarily represent the views of the Committee or the Bury/Bolton ME/CFS Support Group.
All products and treatments featured are for information only.

Editor's Note

Welcome to the first of our new style newsletter. It was with great sadness that in last month's flyer we announced that Tom Nicholson was stepping down as producer of our quarterly newsletters. We wish to repeat our thanks to Tom for all of the hard work he has contributed over the years.

So we need to change the way we do things from now on. We will no longer be able to produce our quarterly magazine, but instead we will be adopting a 'little & often' approach, expanding our monthly flyers into an 8-10 page mini-newsletter, incorporating articles and many of the features you will recognise from the magazine.

Your input is still invaluable to us and we would greatly appreciate you sending in anything you would like to share with the rest of the group. It doesn't have to be an article about ME/CFS, it could be about a holiday or a day out you have had. How about a book review, recipe ideas, poems, helpful tips and suggestions etc. Whether it is a whole page, or just a few lines, it all counts! Please send your contributions to: Dave@mesupportgroup.co.uk, or if you are unable to email, post to Pam Turner (7 Burghley Drive, Radcliffe, M26 3XY).

Or alternatively, if you have an idea, but you prefer not to write about it yourself, then please contact Andrew on 0161 7986183 or andmk1@gmail.com and he will discuss it with you and write it up on your behalf.

We hope you enjoy this issue and would welcome any comments you have to Dave@mesupportgroup.co.uk or 05601 335037.

Carers' Outing

We still have a small number of places left for our free meal out on **Sunday 8th November 2009, 2:30pm** at:

Smithills Coaching House, Smithills Dean Road, Bolton, BL1 7NR.
www.smithills.co.uk

All members are welcome, both carers and sufferers. If you wish to attend, please return your application form and refundable deposit to Pam as soon as possible, but by 23rd October at the latest

There is no charge for the meal and deposits will be returned to you on arrival at Smithills for your afternoon outing, or if you cancel your place in good time (i.e. by Friday 6th November at the latest).

If you have booked, but can't make it after all, please don't forget to let Pam know before Friday 5th November at the latest, for a refund of your deposit.

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. Please call Pam on if you want to know more about the meeting or for a map visit <http://www.mesupportgroup.co.uk> and click on the “Future meetings” page.

Thursday 15th October 2009, 7:30pm, Gail Sumner, who has spoken to us some time ago about her history of ME. She will be updating us on her work using the Perrin technique, and her other observations on ways of managing the illness.

Thursday 19th November 2009: The pre Christmas social with “Bring & Share” buffet supper.

Radcliffe Socials:

Our Social Group meets informally on the first Monday of each month, our next will be on **Monday 2nd November at 4pm**, continuing at our new venue: **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. We have met here several times now and it is proving to be a popular venue. 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 email dave@mesupportgroup.co.uk or phone 05601 335037.

Bury Socials:

These are continuing on the first Thursday of every month, the next meeting will be **Thursday 5th 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:

These 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. Call our instructor Olivia on 01706 829488, or email olivia@oliviayoga.co.uk for details.

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

Bolton/Bury ME Support Group Meeting September 2009:
Debra Seddon, Nutritional Therapist

Debra told us that she has been interested in nutrition since the age of around 13, when her grandmother gave her a nutrition book. Because of her interest, she opened an holistic health club and gym in Southport where she lives. However a few years ago she decided to concentrate on nutritional therapy, she had studied and qualified as a food and nutrition teacher at John Moores University in Liverpool, and has taught in various schools locally. She has done many courses including a 4 year Diploma in Nutritional Therapy, phytotherapy, herbal and nutritional supplementation. Debra takes an holistic view of health and states that the body has a wonderful capacity to heal itself, when we are ill it is the body's cry for help and it will manifest itself where there is a weakness e.g. some people may have weakness of the skin and this may show itself as acne, for others it may be the chest and show as asthma. This may be nothing to do with the illness, it is just your body letting you know that things are not right.

Debra became ill in 1997, she had been on holiday in Thailand and when she came back just thought that she had jet lag until she lost the power of speech and collapsed; she was diagnosed with CFS. As have many of us, Debra went from being a most active person to suffering a complete loss of her active life. Obviously Debra had a lot of information about nutrition and knew that she was eating healthily so she soon realised that she was not absorbing it. She visited a nutritional therapist, also osteopath-Raymond Perrin and spent a lot of money on different therapies. She also used a zapper which is a little gadget which sends small electric currents through the body to kill off any bacteria, parasites etc. She made a very quick recovery but then 2 years ago went back to Thailand and finished up getting a parasitic worm (gardia) and was very, very ill. Even after getting rid of the parasitic worm she still had a lot of the symptoms so she went to see Dr Wright. They worked out that in 1997 she had contracted borrelia and when her immune system went down because of the parasitic infestation, it became virulent again. Borrelia is a very clever organism and when it is attacked, as it was when Debra originally did all her treatments, it goes into hiding in a dormant stage; but as soon as there is opportunity it will start up again with a vengeance. There are ways to get it under control such as antibiotics or herbal remedies. Debra tried the herbal remedy and felt much worse because of the die off effect.

Debra stressed that before you even think of taking antibiotics or herbal remedies it is vital to get your body to optimum health to be able to kill off the borrelia. Debra says that now when doing her blood tests the borrelia is no longer visible but she still has mild symptoms if she over does things and gets too tired. Debra has made a very good recovery.

She then went on to tell us the causes of ME; very often it starts with an initial trauma, such as an illness or an accident or a stressful event which causes the adrenal glands to overwork, this in turn always reduces the body's digestive enzymes and so food is not digested properly. As much of the immune system is supported by nutrients from food, if it is not being digested properly the immune system goes down.

Next, there is usually a genetic tendency towards ME.

There is also research now which shows that there may be an imbalance of calcium and magnesium in patients; many women are deficient in magnesium.

Once the immune system has been damaged, you are then susceptible to parasites or borrelia to take hold.

How do we help the body recover? The body has an amazing ability to repair itself but we must try to get it to that optimum state by using dietary supplements, in order for it to be able to recover it has to have the nutrients it needs. Debra stressed that it is important to be assessed by a nutritional therapist to find out exactly what your body needs because there are so many supplements out there,

you could spend a fortune. She has a special cream that is very easily digested and contains many of the nutrients the body needs.

Debra said that digestive enzymes can be taken with meals and which can help your body absorb the nutrients. A very important thing to note, is that you should not drink anything 1/2 hour prior, during or 1/2 hour after a meal; in order to encourage you to chew food properly and let your body's digestive juices work.

When the body is ill it has a tendency to become acidic so it is important to try to rebalance this and cut down on acidic foods. Debra said that wheat products and dairy products are both acidic and this is why they tend to put an extra strain on the body. She said that no one should have wheat more than once a day. When you are ill you may have sensitivities but once your digestive system recovers you can often tolerate food better.

Some of the supplements that Debra said can be useful are magnesium, vitamin B, good quality fish oils, Co-enzyme Q10. Some of these may be available on prescription. Debra does a scan of her patients to find out where energy levels are high (e.g. If you have inflammation levels will be high) or low: as an illness becomes chronic the meridians become clogged and energy is lower. Some medicines may get rid of a symptom but cause the cells to become clogged up, it is therefore vital to address the problem as a whole and give the body the best possible chance of repair and recovery.

Debra said that your emotions are felt by every cell in your body therefore if you are sad every cell is sad and equally if you are happy every cell is happy. This is why it is very important to meditate and use relaxation to help with recovery. She stressed that the digestive system is the key to getting back to optimum health and to use supplements but only the ones that your body needs. Once you get to optimum health your body can repair itself and you can discontinue many supplements.

When asked about the use of probiotics and prebiotics Debra said that it is very useful, but to ensure that you get a good one.

Debra recommended that people take a glass of warm water with either lemon juice or root ginger first thing in the morning. She said that body brushing is very useful starting at the feet, using circular movements and working upwards. She also said that gentle exercise or stretches can be very helpful and useful.

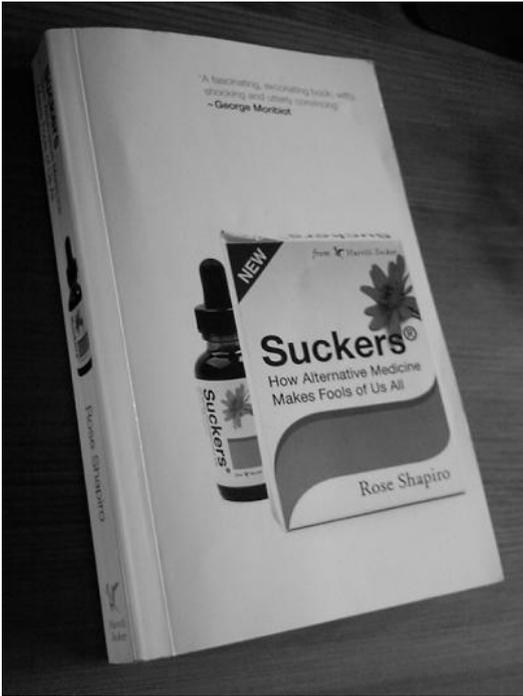
Debra finished by telling us to stay positive, do the bits you can do and try to get the digestive system working.

Debra holds clinics in Bolton and can be contacted on 07703 517988



Huge congratulations to Lynda and Priscilla (the duck), who completed their sponsored cycle of the Great Glen Way a few weeks ago. They are still recovering, so will tell us more about it next month. The sponsorship money is still coming in, but they have already collected over £1000 !!! To add to this, go to:

www.justgiving.com/lyndamarney1



Book Review

Suckers: How Alternative Medicine Makes Fools Of Us All

- By **Rose Shapiro**

Complimentary and Alternative Medicine (CAM) is everywhere and I am sure we have all tried it in some guise or other, whether in the form of nutritional supplements, treatments or therapies, but how many times have you wondered about the science behind it all?

Not only does Ms Shapiro reveal some very interesting and often surprising facts about CAM, but she also gives a step-by-step guide on

how to spot the warning signs that something may not be quite what it seems, or in some cases even potentially harmful. This book is invaluable reading for anyone who already uses, or is thinking of trying CAM. Priced at £8.99 (or £6.74 from Amazon) you may soon find that it pays for itself in helping you to evaluate whether any treatments you are considering are worthwhile or not.

Not that you should necessarily take to heart everything the book says, afterall whilst a particular treatment may not gain the approval of a sceptic, if it helps you to relax or to feel better, then that is really all that matters.

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*Thank you very much to Kathleen, who has
very kindly donated to us a large number of her
handmade cards.*

*Look out for these at our meetings, at our
library table, where we will be selling them to
raise money for the group.*

*Anyone who is interested in joining her card-
making class, call Kathleen on 01204 521147.*

Breathworks are offering free places on their 'Living Well' course to people from Ashton, Wigan & Leigh (sorry no other areas at this time) who are on Incapacity Benefit. There are 180 places available and the courses are in autumn and next spring. If you are eligible and want to take one of these free places, phone Colin at Breathworks on 0161 8341110. Their website is:

<http://breathworks-mindfulness.org.uk/>

Action For M.E.'s Welfare Campaign:

Keeping People With M.E. Off The Poverty Line

Imagine this. A person who, like 77% of people with M.E., has lost their job. They don't have permanent health insurance. Their partner has to care for them so can't work anymore either. The doctor from the Department of Work & Pensions doesn't believe in M.E. so they'll have to appeal to get welfare benefits. Now imagine how the mortgage or the rent will be paid.

This is the reality for thousands of ordinary people with M.E., none of whom choose to rely on handouts. In 2008 the government presented Welfare Reform proposals which threaten to make life even more difficult for these individuals. It aims to cut the benefits budget by forcing people who have long-term conditions back into work. It will rely on employment advisers who are very unlikely to have the specialist knowledge required to assist any one of a wide range of disabled people safely back to work.

Action For M.E. responded to the public consultation, keen to see that the bill was adapted to meet the needs of people with M.E. They ran an online survey and swiftly collected the facts. 62% of those who responded want to work and 48% have found that a benefits assessment has adversely affected their health. They feared that they would be forced to return to work before they were ready and that, as a result, they would suffer a relapse.

Now AFME are engaging at every stage of the political process. They sent a report of the findings, along with a request to raise key questions during the second reading of the bill, to the 140 MPs who register an interest in M.E. AFME have since sent the information to The Countess of Mar who chairs the Forward ME group and to a large number of peers including their own two Patrons in the House of Lords. AFME will continue to intervene with new responses.

Care or Cuts?

The Big Care Debate is the title given to the Government's consultation on proposals for a national care service for adults in England. The Green Paper '*Shaping the Future of Care Together*' was published on 14th July.

Health Secretary Andy Burnham says everyone in England will be guaranteed joined up services and personalised support.

However, information and campaigning website www.benefitsandwork.co.uk says the paper sets out plans to stop paying Attendance Allowance (AA) and the care component of Disability Living Allowance (DLA) and "hand the cash over to social services to administer as part of a personal budget instead.

It quotes welfare benefits consultant Neil Bateman, writing on Rightsnet, as saying: "Based on what I heard last week at the DWP Policy and Strategy Forum, both DLA and AA are in the sights and DWP are closely involved in these developments."

Action For M.E. is looking into this further. Please keep an eye on their website www.afme.org.uk.

Proposals for funding the new care service include sharing costs between individual and state or different insurance options. The consultation will last until 13th November 2009. For more information, go to www.careandsupport.direct.gov.uk.

Thanks to Action For ME

Reminders

Equipment Hire: We have a wheelchair, an electric mobility scooter (small enough to fit in car boot for days out or holidays) and a light box. If you wish to borrow any of these, please phone Pam on .

Library: Please return any books you have to the meeting if possible, so that other members can borrow them. If you have had a book for a long time, please phone Carole on 01942 810320 to let her know you still have it and haven't been able to return it yet. They are costly to replace if lost and we are currently missing around 19 at the moment! We welcome any suggestions for new additions.

Link-Up: If you would you like to be in contact with other members of the Bury/Bolton ME/CFS Support Group by telephone, then you can by joining the Link Up Contact Service. It is very user friendly and it is free to all members of the Support Group. Two contact directories are sent out each year, one in the summer and one during the winter. It is a great way to contact people, compare experiences and most importantly make new and lasting friendships. For further information you can contact Stephen at stewalker@postmaster.co.uk /or call on 01204 842395 (Monday and Friday after 6pm).

Email Chat Group: Our Yahoo! Chat group is another great way of keeping in touch with other members between meetings. Unlike a conventional chat room, contact is made by email and/or message board, so you don't miss out if you are not online when a message is sent and can catch up at any time that suits you. On our Yahoo Group home page we have also built a large database of links to information and services that we have found to be useful.

To join, email dave@mesupportgroup.co.uk or visit:

http://health.groups.yahoo.com/group/Bury_Bolton_ME_CFS_Support_Group/

Neuro Support Groups: These groups provide information, advice and support for people with any type of neurological condition and/or their carers. Guest speakers are in attendance most months.

Bury Neuro Support meets most 2nd Thursdays between 4-6pm at Bury Parish Church Hall (Community transport available).

Neuro Support 4 Salford meets most 4th Fridays (11am-2pm) at varying venues whilst building work is being completed at their regular meeting place.

Call 0161 742 7485 or visit <http://www.gmneuro.org.uk> for information about either group.

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

Help us to be greener: If you would like to receive flyers and/or newsletters by email instead of post, please let me know by emailing dave@mesupportgroup.co.uk.

Benefits & Work Guides: Our group is a member of www.benefitsandwork.co.uk, allowing us to access their fantastic guides to a range of benefits and disability related issues. The guides are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge plus use of the Freedom of Information Act. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal. The group's subscription allows us to email or post these guides to our own members, so please look through the list below and if you need anything phone Dave on 05601 335037 or email dave@mesupportroup.co.uk.

If you have access to the internet yourself you may also want to look through the archive of news articles on their website, unfortunately there are far too many to list here, but if you see anything there that you are interested in, get in touch (as above) and we can send you the relevant article(s) – sorry, but unfortunately we are not allowed to disclose our login details to our own members. You may also wish to sign up to their email newsletter - you don't have to be a member to do this.

DLA & AA

The best possible Attendance Allowance claims on physical health grounds.

The best possible Disability Living Allowance claims for adults on physical health grounds

The best possible Disability Living Allowance claims for adults on mental health grounds.

The best possible Disability Living Allowance claims for children on physical health grounds.

The best possible Disability Living Allowance claims for children on mental health grounds.

70 questions you are likely to be asked at your DLA medical.

The best possible way to challenge a DLA or AA medical report.

The best possible support for clients with DLA and AA appeals.

Appealing against a DLA decision.

Giving persuasive information about how far you can walk.

Challenging the claim a bottle or commode will replace the need for help.

DLA renewal claims.

Changes of circumstances for people claiming DLA.

Letter from claimant to decision maker requesting reconsideration because of additional evidence, DLA.

Incapacity for Work

The best possible incapacity for work claims on mental health grounds.

The best possible incapacity for work claims on physical health grounds.

Exempt but sent a questionnaire?

60 questions you're likely to be asked at your incapacity medical.

ESA

Understanding Employment and Support Allowance

ESA claims for mental health and learning difficulties.

ESA claims on physical health grounds.

ESA appeals.

Permitted Work.

Getting the best from Work Focused Interviews.

Other

If I do any work can I continue to claim my...?

Caution! It may not count as voluntary work.

Am I covered by the Disability Discrimination Act?

Which benefits can I claim?

Reasonable adjustments: Employers and Jobseekers.

Getting better treatment from the DWP.

Getting help with your benefits.

Work and benefits for people with long term health conditions.

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 253 6008 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
ACCESS to WORK: 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 for general enquiries
Welfare Rights Helpline - 01749 330136 9am to 1pm Mon Tues Thurs 9am to 12.30 Fri
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 or for young people with ME 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/

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

CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION:
2 The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. www.cfsrf.com

M.E. Research UK: The Gateway, North Methven Street, Perth, PH1 5PP. 01738 451234 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

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

AYME: Association for Young People with ME, Box 605, Milton Keynes MK2 2X. 08451 232389. 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

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

The Pensions Ombudsman: 020 7630 2200 www.pensions-ombudsman.org.uk/