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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 editor, the Committee, or the Bury/Bolton ME/CFS Support Group. All products and treatments featured are for information only.

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by:
Health
For Bolton**

Angela's experience of Pathways to Work

Angela is CFS/ME sufferer and member of our group. She recently went through a government scheme designed to get people with disabilities back to work and off incapacity benefit. The scheme is called Pathways to Work, and Angela wanted to share her experience in case there are others who have to go through the same process.

After a period of absence from work due to her CFS/ME, Angela went on incapacity benefit. She then went back to work for about six months, became ill and went on incapacity benefit again. A few months later she was called to an interview at the Job Centre and this was where her Pathways to Work journey began. Once she had been interviewed, she was asked to attend a support organisation called the Shaw Trust a UK charity who helps disabled and disadvantaged people to prepare for work, find jobs and live more independently. When she went to the trust she had another interview which required a lot of her personal details, including her bank account. This made her feel exposed and vulnerable. The questions also covered her aims and expectations, her skills, interests and all aspects about her condition, including her medication. Once all this information was collected a printout was produced, and she had to sign it to confirm the information she gave was correct. Angela worried about this, especially because no explanation was given about why the information was being collected or for what purpose it was being used.

As a result of the interview, she was advised to go on an exercise programme at the gym! This was despite Angela making it clear that she couldn't cope with this in addition to work and home life as well. The advisor then explored other avenues such as massage at the local college, as it was more affordable. He also recommended a Condition Management Programme, which used Cognitive Behavioural Therapy (CBT) to help individuals. This was presented to Angela despite the fact that she had been on the NHS expert patient programme, and had already undergone a course of CBT.

It was natural that Angela was anxious about her situation, because if she refused their help, she could lose her benefit. So, she began a course on the Condition Management Programme, which she felt was yet another stress on top of her normal life. In fact this was too much for her as the journey into Bury was taxing enough in addition to the complex nature of the sessions, which also included homework.

At her second interview she was cleared to stop this programme. Shortly afterwards, her doctor said he was willing to write a letter explaining the best way Angela should be treated. Although the letter was not required, she continued to attend a few more interviews. She then took early retirement and this signalled the end of her experience.

The Pathways to Work programme is tailored to each person's individual need. However, Angela recommends that anyone going through the process takes two steps to help themselves. Firstly, when attending the interviews you should go with a friend who can support and represent you. This will help prevent feelings such as, "I have absolutely no control over this situation". Secondly, she felt that help from the GP, or consultant, was essential as the people in this programme were more likely to be less qualified when recommending treatments and solutions about how to improve the condition. Angela says, "If your GP or consultant can get involved, then this could influence their recommendations for a better pathway back to work".

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.

**APOLOGIES FOR THE MISS-PRINT LAST MONTH, OUR
JANUARY MEETING WILL BE ON THURSDAY 21st.**

Thursday 21st January, 7:30pm - Natalie Flack from The Shaw Trust. This organisation helps people who are on sickness-type benefits back into work. If you are a new claimant for ESA (the replacement for incapacity benefit) you may already have had some sessions with them. Eventually all of us on such benefits may have to attend such sessions. Please note: Natalie will not be able to answer any questions about benefits, however we are hoping to have someone to come and talk to us about Employment Support Allowance in the future.

Thursday 18th February 2009, 7:30pm – Sue Hutchins on Ki Therapy.

Radcliffe Socials: Our Social Group meets informally on the first Monday of each month, our next will be on **Monday 1st February 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 05601 335037 or email Dave@mesupportgroup.co.uk.

Bury Socials: These are continuing on the first Thursday of every month, the next will be **Thursday 4th February, 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 01706 829488, or olivia@oliviayoga.co.uk for more information.

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 743 3701 or visit <http://www.gmneuro.org.uk> for information about either group.

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

Living with “me” Dad – by the 12 year old son of one of our members

Many people would think living with a parent with chronic fatigue syndrome is extremely difficult but not in this case.

I would expect to be doing more house chores or having less support when I am doing something important or needing help with my homework in school. However my dad is there for mostly everything.

Sometimes he is a little bit tired and sometimes I do have to help more but it isn't a big factor. At certain points, I worry that my dad is too tired and is being too optimistic when he is trying to achieve a time-consuming task.

Every now and then I do have to tell my dad to have a rest or to stop doing chores that I should be doing at 12 years old.

There are also times when I should be more independent and not ask my parents to help me with things I should be able to do. I usually ask for help on the computer (maybe downloading software or ordering something for me).

I sometimes ask for help at the wrong times when my dad is exhausted from a hard day's work. At 12, sometimes I don't use enough logic to realise that my dad is unable to do something that I want him to do now. This is also a slight lack of maturity.

My dad doesn't usually get angry. If I'm not there to help when he needs it then he won't be too happy.

I also think that my dad is lucky to be married to my mum. My mum does most of the cooking and cleaning in the house which leaves my dad with not much work to do. When my mum is tired, my dad instantly comes to help even though he maybe tired as well. I have to stop him and end up doing the work with my sister.

I think that I take advantage out of what my dad can do with Chronic Fatigue. I should be caring more and helping more as a family member. I am lucky that Chronic Fatigue isn't affecting my dad too badly and I am classified as a lucky child to have such a hardworking dad.

Living with “me” Dad – by the 14 year old daughter of one of our members

My Dad has chronic fatigue. There are times when I forget this and times when it is an obvious matter, and I am now used to my dad having good and bad days.

At the moment I feel my Dad has many more good days than bad. On a bad day he will alert us all and tell us he is feeling low. When this occurs, I try my best to help with the daily household chores, and usually if I help to do the small things in the house it can make a big difference to my Dad's mood.

Dad's chronic fatigue does not make a huge difference to the family dynamics as we are all used to the fact that Dad gets tired easily and should not exert himself. When he is tired we all try our best to help and just let him lie down and rest.

I think that having a Mum and job that is so supportive to dad's illness helps greatly. Firstly Mum understands the extent of dad's problem and can help where necessary. Also Dad says himself that he is lucky that his job is flexible and understands his illness to. For example when he was in no fit state to work a couple of years ago he was still being paid and was given as much time as he needed to try and recover. Now as Dad works at home he is able to go for regular rests during the day to help keep him ok.

I think in order for my dad to recover he needs to help himself. He does not really understand his limits. More often than not my Dad takes on much more than he is capable of and it is up to Mum and I to remind him that he should stop doing this task now and maybe to have a rest. If we do not prompt him Dad would keep working until he is exhausted and in no fit state for anything.

My dad is definitely becoming more controlled and understanding how to deal and live with the illness that he unfortunately has. By reading books on time management etc. he has been able to start helping himself get back to normal.

POSTERS:

Twice a year we send our posters & leaflets to the 71 libraries in the surrounding area, in order to try and reach out to as many people as possible who might need us. We would like to be able to do the same with GP surgeries, but there are just too many for us to tackle, so we would like to ask for your help. We have enclosed a poster and would be grateful if you could ask your local surgery to display it. If you would like any extra posters for chemists/shops/community centres etc., we would be happy to send more copies to you.



BRICKS & MOTOR
INSURANCE

Bricks and Motor Insurance Brokers Ltd
84 Bolton Street, Bury, Lancs, BL9 0LL
Tel: 0161 763 8222 | Fax: 0161 761 7741
Eml: enquiries@bricksandmotor.co.uk
Web: www.bricksandmotor.co.uk

Many thanks to Bricks & Motor Insurance, for arranging an excellent deal for our group's insurance.

Kevin Houghton (General Manager) says: "We are delighted to arrange cover for your group, and we were happy to do this at cost. Our services are extended to all members who will receive my personal attention and an extra discount."

A note from our librarian:

When I took over the group's library, my first major task was to do a full inventory of all our books, CDs and DVDs. What fun that was, especially with a delinquent kitten as my assistant! The plan is to circulate a list of the library's contents to our members, but unfortunately there are still some items that we've been unable to trace.

First though, I'd like to thank everyone who contacted me and told me about, or returned, items they had borrowed. That made the job of cataloguing much easier. Thanks also to those people who have generously donated books and DVDs to our library.

Now I know I've pestered people already about missing items, but could you please check again that you haven't overlooked a book or disc. We want to buy in new publications and widen our range of information, so the fewer things we need to replace the better.

If there is a book or disc you would like to see in our library, please give us your suggestions. If you want to borrow an item that is currently on loan, let me know and I will be happy to reserve it for you.

Here is a list of the missing items:

Books:

The Last Straw – Peter G Campbell
Post Viral Fatigue Syndrome – Lean Chaitlow
Cooking Without __ _? – Barbara Cousins
Climbing Out of the Pit of Life – Darrell Ho Yen
Chronic Fatigue Syndrome – Gill Jacobs
Candida Albicans – Gill Jacobs
The Low GI Life Plan – Lisa Linter
You Are What You Eat – Gillian McKeith
Somebody Help Me – Jill Moss
Practical Aromatherapy – Penny Rich
Look Younger, Feel Better – Scala and Jacques
Living Well With Chronic Fatigue Syndrome
– Mary J Shomon
Self Help For Your Nerves – Dr Claire Weeks
Adrenal Fatigue: The 21st Century Stress Syndrome
- James L Wilson

CD: The Da Vinci Code – Dan Brown

DVD: International Conference – Invest in M.E.

You can contact me by phone on:

01942 810320.

Or email: carole.senior@tiscali.co.uk

We have heard from our friends at Benefits & Work, that a new shorter 4-page version of the DLA renewal form has recently been introduced. They warn us that people are being turned down after using this new short form and advise anyone who is sent one to consider using the old 50-page form in order to make sure they give enough detail about any changes to their condition. They are in the process of producing a guide to the new form and as soon as they do we will let you know and make it available to you.

ROUGH GUIDE TO ACCESSIBLE BRITAIN

**This book is FREE to
Blue Badge Holders
(normal cost £6.99).**

**Order a copy online at:
www.accessibleguide.co.uk**

Or phone: 0800 953 7070

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 make these guides available 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.

Please note that some of the guides are very lengthy (up to 88 pages) and so it can work out rather expensive for us to print and post them. After each guide listed below, is the number of pages in brackets, to give you a rough idea what it costs us to print and post them to you, here are a few figures:

10 pages - £1.00

20 pages - £1.80

40 pages - £2.70

60 pages - £3.50

100 pages - £5.50

200 pages - £11.00

If possible please help us to keep costs down by providing an email address we can send them to, if you do not have internet access yourself, perhaps you have a friend or relative who could help out. Alternatively, if you go to one of our meetings, social groups, or yoga classes, you could pick them up from there and then return to us to be used again. We don't want anyone to miss out and will do our best to accommodate your needs, but perhaps if you do need us to post any of the longer guides to you (or several of the smaller ones), and you can afford to make a contribution towards the costs, it would be very much appreciated.

WE NOW HAVE SOME OF THE MORE POPULAR GUIDES AVAILABLE FROM THE LIBRARY AT OUR MEETINGS – IF YOU CAN'T SEE THE ONE YOU WANT, PLEASE ASK!

DLA & AA

The best possible Attendance Allowance claims on physical health grounds (44)

The best possible Disability Living Allowance claims for adults on physical health grounds (61)

The best possible Disability Living Allowance claims for adults on mental health grounds (53)

The best possible Disability Living Allowance claims for children on physical health grounds (65)

The best possible Disability Living Allowance claims for children on mental health grounds (58)

70 questions you are likely to be asked at your DLA medical (5)

The best possible way to challenge a DLA or AA medical report (28)

The best possible support for clients with DLA and AA appeals (41)

Appealing against a DLA decision (16)

Giving persuasive information about how far you can walk (13)

Challenging the claim a bottle or commode will replace the need for help (8)

DLA renewal claims (6)

Changes of circumstances for people claiming DLA (8)

Letter claimant to decision maker requesting reconsideration because of additional evidence (3)

Incapacity for Work

The best possible incapacity for work claims on mental health grounds (43)

The best possible incapacity for work claims on physical health grounds (48)

Exempt but sent a questionnaire (7)

60 questions you're likely to be asked at your incapacity medical (3)

ESA

Understanding Employment and Support Allowance (43)

ESA claims for mental health and learning difficulties (88)

ESA claims on physical health grounds (65)

ESA appeals (35)

Permitted Work (6)

Getting the best from Work Focused Interviews (11)

Other

If I do any work can I continue to claim my...? (4)

Caution, it may not count as voluntary work (5)
Am I covered by the Disability Discrimination Act? (9)

Which benefits can I claim? (9)

Reasonable adjustments: Employers and Jobseekers (8)

Work and benefits for people with long term health conditions (7)

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
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 - 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 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.mereseach.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/

