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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	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)
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Membership Secretary, Newsletters & Distribution:	David Gore	07919 234256 Dave@ mesupportgroup.co.uk
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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.

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.

20th January 2011 - Alistair Mirfin, Bury Carers' development worker, will talk about his work, and the outreach service.

17th February 2011 – speaker to be confirmed.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 7th 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 07919 234256 or email dave@mesupportgroup.co.uk. **Don't worry about getting to the venue and not being able to find us – just phone 07919 234256 when you get there and we will find you!**

Bury Socials: These are continuing on the first Thursday of every month, the next will be **Thursday 3rd February, 3pm** at **The Automatic, next to the Met theatre** (it is across the street from Yates, not the Met Café next to Yates), **Derby Hall, Market Street, Bury, BL9 0BW**. http://themet.biz/location/find_the_met.pdf.

If you need any more information, please phone Sheila on 0161 7970026 after 12noon.

Yoga Classes: Are **3:15pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 07746 197511, or olivia@oliviayoga.co.uk for more information.

Neuro Support Groups: These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about meeting times and locations.

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

Everyone who attended the meal at the December social had a thoroughly lovely time.

For those who opted for one of the February meals, you should find a letter with more details enclosed with this newsletter – if your letter is missing, please contact Dave.

If you are unable to attend and need to cancel your meal, please let Pam know by the Thursday before the meal at the latest.

Dr Charles Shepherd
(Medical Adviser to The ME Association) will be speaking at the Stockport ME Group on **Friday 8th April**.

Doors open **10:30am** for an 11am start, at The Toby Carvery, 271 Wellington Road, Heaton Chapel, SK4 5BP.

Library Update

We have recently added quite a few items to our library list.

First, the books bought with the grant which Pam secured for us. Thanks to everyone who offered suggestions; if your choice isn't included here, we now have a wish list of titles ready for our next windfall!

- Mary Burgess – Overcoming Chronic Fatigue
- Emily Collingridge – Overcoming Severe ME/CFS: A Guide To Living
- Christine Craggs-Hunton – How To Manage Chronic Fatigue
- Dr Kenneth Hamably / Alice Muir – Coping With A Stressed Nervous System
- Jesse Lynn Hanley / Nancy Deville – Tired Of Being Tired
- Louise L Hay – You Can Heal Your Life
- Radar Guide – If Only I'd Known That A Year Ago
- Sue Pemberton / Caroline Berry – Fighting Fatigue
- Catherine H Sanders – Understanding Severe ME
- Rose Shapiro – Suckers: How Alternative Medicine Makes Fools Of Us All
- Jacob Teitelbaum – From Fatigued To Fantastic
- William Wolcott / Trish Fahey – The Metabolic Typing Diet

Next we have items which have been donated.

- Alex Howard et al – Secrets to Recover (2nd copy)
- (DVD) International Conference On ME/CFS: Biochemical Research (Cambridge 2008)
- Dr Michael Midgely – A Life Worth Living: A Practical Guide to Living With ME
- Rough Guide to Accessible Britain 2010

Finally, information and support for carers:

- Wealth Check For Carers – Bolton Carers Support 2010
- Bury Carers Guide – A Guide to Caring in Bury

Have you stopped working within the last 6 years? **If so, did you check if you were due a tax refund?**

If you have finished work part way through the tax year, you may have paid too much tax. This is because of the way the tax is automatically deducted on the assumption that you will continue earning a similar amount for the whole of the year. **Do not** assume that if this is the case the tax office will let you know, you may need to get in touch with them and ask.

One of our members was in this situation, having finished work 4 years ago and has just received a £1250 refund.

There is a simple (and anonymous) tool for calculating if you are owed a refund on the HMRC website: <http://stccalculator.hmrc.gov.uk>

To claim your refund, phone the tax office on **01355 359022**. There are no forms to fill in and it really is a very simple process that can be sorted out with a quick phone call.

Disability Living Allowance to change to the Personal Independence Payment – Government wants your response

The Department Of Work And Pensions is holding a public consultation about changes to the Disability Living Allowance (DLA). Whilst they support the principles of the DLA, they want to make sure it is easier to understand and is clear in the awards made to each person. As part of this change, the DLA will be renamed the Personal Independence Payment. The main features are as follows:

- It will be a cash payment to help disabled people overcome the barriers they face to living an everyday life. It will be divided into a “mobility” element to assess the needs for a person to get around. The other component will be described as “daily living”, which will assess the person's ability to carry out their daily life.
- DLA Care Component currently has 3 levels, but its replacement will only have 2.
- Resources will be directed to people who face the greatest challenges; i.e. they must have a long-term health condition.
- Individuals will have to qualify for the benefit for a period of six months and be expected to continue to qualify for a further six months before an award can be made.
- There will be no automatic entitlement to the benefit unless you have a terminal illness.
- The new assessment will focus on an individual’s ability to carry out a range of key activities necessary to everyday life. There will be a number of people involved in the assessment, which is also likely to include an independent healthcare professional. The assessment will also recognize conditions which are “variable and fluctuating” (*NOTE: This could apply to people with chronic fatigue who have good days and bad days*).
- In the past the DLA mobility assessment would have ignored, for example, the use of a wheelchair. In this new system the wheelchair, or any other aid, will be taken into account to assess how a person can cope.
- The payments will be dynamic, which means it will change according to people's circumstances. Therefore, reviews will take place over time to make sure the right benefits are being paid.
- The government recognizes that the existing DLA gives people access to other services such as adult social care. They will account for this in the new system.
- The new benefit will be introduced in 2013/14
- Support will continue to be provided to children and adults up to the age of 65. Individuals who receive the benefit before reaching 65 may continue to receive the benefit beyond that if their needs continue.

The government would like to encourage, where possible, people to take up work and not have to be dependent on the state for their income. They also want to make the scheme affordable because of the vast numbers of people who are claiming it. Their agenda is also driven by cost and the need to make savings on a scheme which they can’t control.

The government is especially encouraging disabled people and interested organisations to respond to the consultation. People have until 14 February 2011 to send in their responses.

To find details of the consultation, please go to:

<http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf> .

If you don't have access to the Internet, you can request a copy by contacting:

DLA Reform Team, 1st Floor, Caxton House, Tothill Street, London, SW1H 9NA

Telephone: 020 7449 7688 - answering machine only

Textphone: 18001 020 7449 7688 - answering machine only

Fax: 020 7449 5467

Email: consultation.dlareform@dwp.gsi.gov.uk

Development of Educational Resources for GPs

Dr Carolyn Chew-Graham GP and Professor of Primary Care, University of Manchester is hoping that the ethics committee will approve her application for a study regarding ME.

The main aim of the first phase is to develop an education and training package for GP practices to help them to be able to make an early diagnosis of ME and to enable them to help and support patients, for both GPs and the practice nurses. This resource will be developed in consultation with patients and carers as well as health care professionals from within primary care, and also ME staff from secondary care (hospitals, rehabilitation centres etc).

It is essential that this work is of the highest quality and the research group will hold a number of focus groups and interviews with patients, carers and health professionals. They will then analyse the data collected to help them develop material for both patients and professionals.

Dr Chew-Graham has asked for our help in this research and I hope that in the New Year you will all do your best to respond to questionnaires and if at all possible come along to any discussion groups in order to give your valuable experience and opinion.

Chocolate Brownies (with gluten/dairy free option)

Following requests at our pre-christmas social, here is the recipe for the chocolate brownies. They really are quite easy to make and luxuriously delicious. This makes just over a kilo of cake, so you may wish to halve the recipe if required, although it does freeze well so why not make a stock to keep.

400g caster sugar

225g butter (or non-dairy baking fat)

60g cocoa

4 eggs

225g plain flour (gluten free if required)

½tsp baking powder

½tsp salt

200g dark chocolate (finely chopped)

Melt the butter/fat and mix into the sugar. Add the eggs, followed by the rest of the ingredients (**except for the chocolate**). Mix well, then add half of the chocolate and mix some more.

Spread out evenly into a greased baking tin (approx 8inch x 12inch, and at least 1½inch deep).

You should still have half of the chocolate left at this stage, sprinkle half of that on top and place in the oven at 180C, gas mark 4, for 20-30 minutes. Once removed from the oven, sprinkle on the remainder of the chocolate and allow to cool before slicing.

Energy Saving Tips: Next autumn we would like to run an article with your ideas and suggestions for how to get through the festive season whilst still trying to preserve energy (and money). While it is still fresh in all of our minds, if you have anything you would like to share with us, please do get in touch.

NHS CFS/ME SERVICES

Whilst the situation in Greater Manchester has radically improved in recent years with new Multidisciplinary Team Services being set up across most areas (but not yet Trafford or Rochdale!); more NHS consultants specializing in ME diagnosis/treatment and a new Children's Service now covering all Greater Manchester's severely affected ME children – there is still 'much room for improvement' regarding GPs diagnosing the illness speedily and providing appropriate management/treatment and long-term ME patients, in my view, still get a raw deal. Hopefully this list of consultants and various services will be of help to those wishing to get a diagnosis or get expert help to improve their recovery.

NHS Choices

Since January 2009 patients cared for by the NHS in England have had a new legal right given by the NHS Constitution to make choices about the services that they receive. This includes the right to choose a GP surgery; to state which GP you'd like to see; to choose which hospital you are treated at and to receive information to support your choices.

For example, anyone wishing to get a diagnosis of CFS/ME confirmed or reassessed due to say new symptoms may ask their GP to be referred to a named consultant.

At the time of writing, I understand that GPs, in say Stockport, can refer patients directly to a consultant without seeking approval from the PCT. For anyone living outside Greater Manchester or anyone seeking say inpatient treatment (which costs £10,000s) your GP would have to seek funding approval from your PCT to refer you.

For more information visit www.nhs.uk/choicesinthenhs

Greater Manchester NHS Consultants with a specialist interest in CFS/ME

Leigh Infirmary. Dr Tarek Gaber, Rehabilitation Medicine Department Tel. 01942 264 321. Ashton, Leigh & Wigan PCT areas covered. Neurology specialism. Very interested in severe ME patients: very occasionally may accept 'out of area' referrals.

North Manchester General Hospital. Dr Patrick / Dr Snowden, Rheumatology Department. Tel. 0161 720 2622. Oldham, Bury, Rochdale, Tameside & Glossop, Stockport and Manchester PCT areas covered. Dr Patrick will also see patients privately.

Royal Oldham Hospital. Dr Sarah Burlinson, Psychological Medicine Department. Tel. 0161 627 8330. Oldham PCT area covered

Salford Royal Hospital. Dr Annice Mukherjee, Endocrinology Department Tel. 0161 206 7049. Salford PCT area covered and also accepts 'out of area' referrals.

Stepping Hill Hospital. Dr Talbot, Neurologist at MRI does clinics at SHH. Tel. 0161 419 5840. Stockport PCT area covered. Dr Philip Lewis, Cardiology Department will now only see ME patients privately. Tel. 01625 540 230.

Greater Manchester NHS CFS/ME Multidisciplinary Teams

East Manchester CFS/ME Service. Tel. 0161 426 5481. Adults; Stockport, Oldham, Manchester, Tameside and Glossop PCTs only. Clinician: Dr Annice Mukherjee

Bolton & Bury CFS/ME Service. Tel. 01204 432 765. Adults; Bolton & Bury PCTs only. Clinician: Dr Andy Wright

Ashton, Leigh & Wigan CFS/ME Service. Tel. 01942 264 321. Adults; Ashton, Leigh & Wigan PCTs only. Clinician: Dr Tarek Gaber

NHS CFS/ME Hospital-based Services

Salford Royal Hospital. Tel 0161 206 7049/5153. Adults; Salford PCT and 'out of area' referrals. Clinician: Dr Annice Mukherjee; ME nurse, CBT, physiotherapy.

North Manchester General Hospital. Tel 0161 720 2622. Adults: Note: CFS/ME Clinic now closed. Clinicians: Dr Pattrick / Dr Snowden refer patients to a physiotherapy "Exercise for Life" programme.

NHS Specialist Service for Severe CFS/ME

Greater Manchester Clinical Network Coordinating Centre. Tel 0161 219 9420.

ME specialist nurse Gill Walsh and physiotherapist Karen Bradbury.

A domiciliary service for adult patients living in Greater Manchester, who are house/bedbound and do not have a local CFS/ME Multidisciplinary Team. Patient's PCT required to fund the service.

NHS CFS/ME Service for Children and Young People

Royal Manchester Children's Hospital. Contact 0161 701 4516, Alex Moore ME Specialist Nurse. Children and young people to age 16; Clinicians: Dr Paul Abeles/Dr Sam Kannan, occupational therapy, physiotherapy. Now accepts referrals from across Greater Manchester. Provides a direct clinical service for more severe/complex cases and offers guidance to local clinicians caring for children with mild CFS/ME.

NHS Inpatient Services

The National Essex Neurosciences CFS Inpatient & Outpatient Service.

Prof. Leslie Findley Consultant Neurologist uses a holistic multidisciplinary approach. Provides diagnosis, treatment/management and rehabilitation to severe and very complex CFS/ME cases, as inpatients. Also provides outpatient service for mild/moderate cases. PCT agreement required to fund the treatment. (Average inpatient stay 3 months). Tel. 01708 435 044 for details.

Leeds CFS/ME Service

A Multidisciplinary Team Service providing assessment, diagnosis and management/treatment and rehabilitation. Provides an inpatient service at Leeds General Infirmary. Led by Dr Russell Saxby, a Liaison Psychiatrist, for moderate/severe/complex CFS/ME patients. (Average inpatient stay 4/6 weeks). PCT agreement required to fund the treatment. Tel 0113 392 7140 for details.

Note: both services may accept private patients

New Private Inpatient Service. Chester - St Cyril's Rehabilitation Unit.

A Multidisciplinary Team Service providing assessment, diagnosis and management/treatment and rehabilitation. Led by Dr Azer, Rehabilitation Consultant. Specialist Neuro Rehab Unit for severe ME patients. (Initial 6 weeks inpatient) Self-fund/PCT agreement required to fund treatment. Tel. 01244 665 330 for details.

Note: for more information about CFS/ME; diagnosis; treatment and the Greater Manchester NHS Services listed visit: **www.manchestercfsme.nhs.uk**

This information was compiled by the Stockport ME Group and they would welcome your feedback on the NHS Services and any problems getting a referral. Please send any comments to Dave (07919 234256 or Dave@mesupportgroup.co.uk) and we will forward them on your behalf.

From Hermes (Dec10), with thanks for their kind permission to reproduce.

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 – 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 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/