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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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Link Up Co-ordinator:	Stephen Walker	01204 842395 stewalker@postmaster.co.uk
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Roving Reporter:	Andrew Levy	0161 798 6183 andmk1@googlemail.com

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.



Dates For Your Diary

Longsight Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

Thursday 20th May 2010, 7:30pm – Charles Tully on the Alexander Technique.
Charles will explain this technique and how it could benefit everyone, by practical demonstration. The Alexander Technique is an approach to co-ordination and movement to correct our bad habits, to relieve stress, aches and pains, and to save energy.

Thursday 17th June 2010 – Social.

Thursday 15th July - Hugh Templeton will conduct his ever-popular watercolour workshop. You won't need any materials, and should go home with a completed painting.

Radcliffe Socials: Our Social Group meets informally on the first Monday of each month, our next will be on **Monday 7th June 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 3rd June, 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 01706 829488, or olivia@oliviayoga.co.uk for more information.

Please note , there will be no yoga on June 8th, classes resume the following week.

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 BASIC, 544 Eccles New Road, Salford, M5 5AP.

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.

Phil's Story

My name is Phil Pearson I was first diagnosed with M.E. by Dr Patrick at North Manchester General Hospital in 1993. When I was diagnosed with M.E I kept my employer fully informed. Other medical history includes being born with Asthma and also with Gilberts Syndrome, which is a hereditary liver condition. I also contracted Glandular Fever in 1972. I had been employed by my employer Rochdale Council since November 1989.

My story starts in 2008 however the 5 or so years leading up to this are important because it was then that my health started deteriorating and I frequently needed to take more and more time off work. I frequently contracted viruses, this would impact on my Asthma and my recovery time seemed to constantly increase, as did the fatigue. In November 2007 I contracted a virus and with hindsight returned to work too early. After the Xmas holidays I found myself off work again. I was so concerned about my health situation that I asked my GP for a referral to an ME/Chronic fatigue specialist.

In February 2008 I returned back to work my GP suggested I went back on a Thursday so I wasn't working a full week. Those two days were dreadful I wasn't functioning properly I couldn't think straight and I could barely stand up let alone walk. Then at the weekend my symptoms of ME worsened, I tried to walk but my legs wouldn't do what I wanted them to do, I couldn't walk upstairs I had to crawl up to my bedroom and I came downstairs on my bottom. I lost my coordination, I was terribly fatigued and I got all the cognitive symptoms of ME, dizziness, anxiety, confusion etc I slept virtually all day and night. My then GP signed me off work until I had my appointment with Dr Wright in March.

The outcome of my meeting with Dr Wright was that he confirmed that my symptoms were a flare up of ME and he insisted that I needed to have absolute rest and take at least 3 months off work. He said I was to be allocated a place on the management programme for ME as soon as a place became available and that he would review me again once I had completed the programme. I kept my employers fully aware of the situation.

My employer's response was to send me to see the occupational health doctor at the end of April. Apparently they wanted to know if the doctor could ascertain when I would be fit to resume work and if I satisfied the conditions for ill health retirement. The outcome was that the doctor couldn't ascertain when I could go back to work and agreed that Dr Wright needed to be given time to reach an informed decision on my long term prospects. She confirmed at that stage that I didn't meet the requirements for ill health retirement.

I was then visited at home by my immediate line manager, the Council's welfare officer and my Trade Union representative were also present. I was informed that the Council were considering dismissing me on the grounds of medical incapacity. I told them I was astounded about this as I felt my specialist should be given the time he needed to complete his investigations and make an informed decision about my health.

My Incapacity hearing was arranged for the end of June 2008. When I was notified of this I went through a range of emotions anger, helplessness despair etc. I had worked for my employer for nearly 19 years and when I needed their support and understanding I felt they deserted me. The stark reality was that if I lost my job I would probably lose my house as I wouldn't be able to pay my mortgage. However once I had let these feelings go I treated the situation, as would a new project at work or an assignment at university/college and had a very positive attitude. I contacted a host of agencies, ACAS, my Trade Union, Equal Opportunities Commission, Action for ME and I also had lengthy phone conversations with Pam Turner. At this time a friend of mine who also suffers with ME and had recently had employment problems introduced me Bridget Fox who works for Bury Employment Support and Training (BEST). Bridget was an absolute inspiration, she

basically told me that I had two options: I could roll over and let this happen to me with the possibility of losing all I had worked for or, I could fight all the way to get justice.

Bridget introduced me to a solicitor (Kevin McKenna) who she had used previously where disabled people had been discriminated against. Kevin has an excellent record of winning these types of cases. Kevin was very honest about my chances of success and tried to dissuade me from using his services because of the potential cost to myself. He suggested that I try using the Trade Unions solicitors or if that failed then to check my house insurance because unknown to me at that time if you take out legal cover you are usually covered for employment issues. However the legal people at my Trade Union wouldn't take the case and I wasn't covered by my house insurance so I employed Kevin as my solicitor.

Leading up to the Incapacity Hearing I gathered as much information/evidence as possible to use in my defence. I also submitted a grievance to the Council mainly in the hope of delaying the Hearing. This didn't work the Council responded to my Grievance at the Incapacity Hearing. The Hearing was like a slow torture. I really had to attend in person though I could barely walk. Once again Bridget came to my aid as both physical and mental support. Whilst I consider myself to be a reasonably intelligent person the cognitive symptoms from ME that I was experiencing meant that my understanding of what was going on around me was very limited. Although the Council acknowledged that Dr Wright had not been given time to complete his investigations they went ahead and sacked me without access to my pension. As you can probably imagine following this decision my ME conditions worsened considerably.

I appealed this decision. At times I wished I hadn't because when I felt my health was at my lowest point and my body was screaming for rest I had to find the energy and strength to put my appeal together. Sometimes I would be sat at the computer in tears through pain and fatigue. But something kept me going I knew I was right to fight and I couldn't give up.

The appeal was on 1st October 2008. At the appeal once again I was supported by Bridget and my Trade Union rep. I read my prepared statement out (I had to use a prepared statement as my word loss at this point was terrible). This was my opportunity to express to a supposedly independent panel about how I felt about the action that had been taken against me and why I had been unfairly treated. I felt we had won the arguments at the appeal but a few days later I received an official letter confirming that my appeal had failed. Again following this decision my symptoms of ME worsened.

Desperation could have kicked in at this point but just after the appeal Dr Wright gave me the news that it was his considered opinion that I would not be able to work again. So whilst this is not the ideal news anybody wishes to hear it did at least open the door for me to try and access my deferred pension rights. I attended a medical with the Council's Occupation Health service at the end of December 2008. The result was that it was recommended that I should receive my deferred pension benefits. This meant I would receive part of my pension but nothing like the amount had I been retired on the grounds of ill health. What it did mean though is that I would be able to stay in my house and pay the mortgage.

Following the appeal virtually all mine and Bridget's work was done I handed everything over to my solicitor Kevin who then got the legal ball rolling through the Employment Tribunal to claim unfair dismissal against the Council and to seek reinstatement with the sole purpose of accessing my full pension rights. The case law that my solicitor used was that of Haigh v First West Yorkshire Bus Company. Where Haigh had been dismissed by his employers without allowing the medical specialist of Haigh enough time to reach a considered opinion of his long term medical outlook.

In May 2009 I attended the Employment Tribunal in Manchester again aided with tremendous support from Bridget. What a daunting experience! I experienced a multitude of emotions but the

overriding feeling I had was that this was going to be my day and I wouldn't have missed it for anything. The Judge's attitude was in complete contrast to that of my former employers he demonstrated he had compassion and an understanding of the difficulties faced by people with disabilities. He was at pains to put me at ease from the outset. He acknowledged that going through this process must be traumatic and recognised that it would have an impact on my disability and offered to take a break from the proceeding as and when I needed one.

After the opening exchanges by both sides the Judge requested that Rochdale Council reconsider their defence, as it seemed their case was indefensible in the light of the case law. Rochdale refused and continued with their defence. Throughout the morning time and time again the managers from Rochdale were made to look like bumbling idiots by my legal team. At the break for lunch the judge again requested that Rochdale reconsider their position. Once again Rochdale declined and carried on their defence. This meant that I had to take the witness box in the afternoon, another daunting experience but the way I looked at it was that this was my big opportunity to demonstrate how flawed the action to sack me had been. Once I had given my evidence I felt a great weight had been lifted off my shoulders.

At the end of the hearing it took the panel 10 minutes to reach their decision. The verdict was that I was unfairly dismissed and must be reinstated to then be retired on grounds of ill health with access to my full pension rights. The judge in his summing up condemned Rochdale and the actions they had taken and questioned the competency of the people who had taken the decision to sack me.

What a relief and what a result and I was so glad it was all over. But why should people like us be treated in this manner? Because we're easy targets and are not expected to fight back?

During this process I have learnt a lot about myself. It was a long process but I never gave up hope. I found strength to fight and I always had faith and a positive outlook that it would all come right in the end. I feel very lucky that I have ended up where I am it could have turned out a lot worse and I am aware that for some people it does turn out a lot worse. However I hope that this example gives others in a similar situation the hope and motivation to carry on and fight the injustice that is put upon us.

There have been many learning points throughout this process, I have listed the main ones below

- Get the facts about the situation from the professionals e.g. ACAS, Action for ME etc.
- Surround yourself with people who can help you.
- Don't be too proud to ask for support. The support is out there it's a question of finding. (I consider myself to be a very independent person but I found that I have never asked for so many people for help in my life).
- Be strong. It's amazing how strong you can be even when you feel at your worst.
- Have faith, whatever that faith may be and don't lose it.
- Don't rely on your Trade Union to be pro active. I felt terribly let down by my Union whose solicitors refused to take my case.
- Don't be discouraged by setbacks.
- Be careful who you listen to.

I am indebted to so many people who have helped me along the way but I would like to say a big thank you to Pam Turner and Dr Wright and his staff for being fantastic and to Bridget and Kevin for giving me the hope and encouragement to see this through to the end.

I would be happy to talk to any of our members who might be going through something similar.

Contacts: Phil Pearson: 0161-764-2817
Bury Employment Support and Training: 0161-761-4662
Kevin McKenna, Senior Associate Weightmans: LLP 0161- 233-7330

ME RESEARCH UK - ON LOW-DOSE NALTREXONE

Continuing our regular series featuring stories from Breakthrough, the magazine of ME Research UK, by Dr Neil Abbot. Articles have been extracted from the Autumn 2009 issue. Read the magazine online at www.meresearch.org.uk or contact: ME Research UK, The Gateway, North Methuen Street, Perth PH1 5PP. Tel: 0 1738 451234. E-mail: meruk@pkavs.org.uk.

Naltrexone hydrochloride has been used clinically for many years to treat opioid addiction. Recently, there have been suggestions that naltrexone at 3 to 4.5 mg per day (low-dose naltrexone, LDN) might be beneficial for chronic pain and autoimmune disorders, and open-label pilot trials of LDN for Crohn's disease and multiple sclerosis have been conducted. A recent paper (*Pain Medicine* 2009) reports its use for fibromyalgia, a chronic pain disorder with a diagnostic overlap with M.E./CFS.

Small scale test

Ten women with fibromyalgia received a placebo for two weeks followed by LDN 4.5 mg for eight weeks, and then a two-week 'washout' period. They completed reports of symptom severity every day, and also visited the lab every two weeks for tests of mechanical, heat and cold pain sensitivity.

Overall, LDN seemed to have a beneficial effect: key symptoms of fibromyalgia were reduced by 32.5% with LDN compared with 2.3% for placebo ($p=0.003$). Not all patients responded, and only six out of ten showed more than a 30% decrease in symptoms. However, women with evidence of general inflammatory processes had the greatest reduction in symptoms.

While it's impossible to conclude much from a small pilot study in which only some of the patients responded to the drug, the findings are certainly intriguing. And the proposed mechanism of action (reduction of inflammation by suppressing central nervous system microglia cells) suggests that a clinical trial of LDN for M.E./CFS patients might be worthwhile, given that there is evidence of an ongoing inflammatory process in some patients.

With thanks to InterAction



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 01204 793 846.

Amazon: Don't forget, 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.

CAN AND DO PEOPLE RECOVER?

Dr Neil Abbot, ME Research UK

Recovery from M.E./CFS is a very interesting and important topic – and one rarely examined. A quick look at the scientific literature seems to show that 'recovery' is a real possibility, though full-recovery rates are quite low. For instance, Dr Melvin Ramsay, referring to classical Myalgic Encephalomyelitis, considered that complete recovery appeared to "be confined to one third of cases, predominantly young people who have been able to rest from onset of illness" – implying that recovery in adults alone was a considerably lower figure.

Looking at chronic fatigue syndrome (in all its various definitions), reported rates of recovery in a few small studies have been less than 20%, and have varied from study to study due, at least in part, to differences in diagnostic definition. Nevertheless, the research literature shows that recovery is a real possibility for some people with M.E./CFS – a fact which accords with real-world experience; from ME Research UK's experience alone, we have had many phone calls over the years from people who say they have recovered, using a multitude of therapies or none at all.

The evidence suggests that recovery is more likely to happen early in the illness, and to be far more likely in children than adults, but what we don't know is how full or complete any particular recovery really is (something the patient themselves might not know for sure).

There is one vital thing to remember, however: that the real, on-the-ground recovery rate from M.E./CFS might be far higher than the (low-ish) recovery rates reported in the research literature. Take a patient who has been given a diagnosis quickly by a GP (using, say, the NICE Guideline of 2007), has been ill for six months only, and then fully recovers. The person will not appear in a research study, will be unlikely to join an M.E. campaigning charity or local ME group, and will disappear back into the workaday world without registering on the M.E./CFS radar as a recovery. The only way to know true recovery rates would be to identify M.E./CFS patients at the point of early diagnosis, and prospectively follow them through for many years. The results might just surprise us all.

Professor Tony Pinching

Yes, people can and do recover, but in different ways and at different rates. Quite a proportion with short periods of illness (a year or two) seem to recover to their previously 'normal' levels, and this may be commoner in young people. Many of these don't get to see specialists or join groups, so they are often not counted when people give figures. But it happens: they definitely had CFS/M.E. and they did get better.

It is a myth that people who have been ill for longer than 'x' years can never get better. Some people can and do recover after prolonged and severe illness. I have been pleased to witness that in patients of mine after 5, 10, even 20 years.

However, many people who have had M.E. will come to re-define what 'normal' is. These are people who have understood, through learning how to manage it, what the illness signifies for them. They review their priorities and reassess what they spend their energies on, even when they are feeling well. They may reflect that what they were doing before they were ill was not sensible, and do not wish to revert to that. Also, some people may be content with a level of function that may not be '100%' (whatever that is?!), but a different level that still allows them to do everything that they need and wish for. So for many, the word 'recovery' is not about going back to what they did before, but to something better, more sustainable, and ... wise!"

Taken from the article in InterAction with our thanks

For anyone who hasn't already done so, please don't forget to send in your membership renewal forms. If you have forgotten whether or not you have renewed, or have lost your form and need another, you can call Dave on 05601 335037 or email Dave@mesupportgroup.co.uk.

SOME CONTACTS YOU MAY FIND USEFUL

ACCESS to WORK: http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev_015798.xml.html

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

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

Basic Neurocare Centre (inc Assisted Gym): 554 Eccles New Road, Salford, M5 2AL: 0161 707 6441

Benefits Agency Information Officer: Bolton - 01204 367000 Bury - 0161 762 2000

Benefits Helpline (to request DLA forms): 0800 882200. **For Help Completing Forms:** 0800 44 11 44

Bolton Community Voluntary Services: 01204 546010 **Carers Support (Bolton):** 01204 363056

Bolton Primary Care Trust: 01204 907724

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

Bury Carer Services: : 0161 763 4867 and **Bury Carer Assessment:** 0161 253 7190.

Bury Council for Voluntary Services: 0161 764 2161

Bury Primary Care Trust: 0161 762 3100

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.

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

Citizen's Advice Bureau: Bury - 0161 761 5355 Bolton - 01204 900200 (/213 Housebound)

COMMUNITY LEGAL ADVICE: 0845 3454345 www.communitylegaladvice.org.uk

DIAL Disability Information and Advice Line: equipment/gadgets and where to get them: 0161 703 8887

Disabled Living: 0161 832 3678

Equality Human Rights Commission (was Disability Rights Commission): 0845 604 6610

General government guidance on entitlements: <http://www.direct.gov.uk/DisabledPeople>

INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS): help with NHS complaints: 0845 120 3735

JOB CENTRE PLUS: http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled_People_and_Carers/index.html

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

NATIONAL ME SUPPORT CENTRE: Disabled Services Centre, Harold Wood Hospital, Romford, RM3 9AR. 01708 378050 <http://www.nmec.org.uk>

Ring & Ride: Bolton - 01204 388500 Bury - 0161 764 1999

SHOPMOBILITY: Bolton – 01204 392946, **Bolton Market Place - Wheelchair Service:** 01204 361100, **Bury –** 0161 7649966, **Manchester Arndale -** 0161 839 4060, **Trafford Centre:** 0161 749 1728.

Social Services: **Bolton** 01204 337841 **Bury** (town hall) – 0161 253 5000 (ask for adult social care team)

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

The Pensions Advisory Service (TPAS): 0845 6012923 www.pensionsadvisoryservice.org.uk

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

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

Welfare Rights Advice Line: 01204 380460

www.writetothem.com - type in your postcode to find out who is your MP/MEP/councillor & how to contact them.