

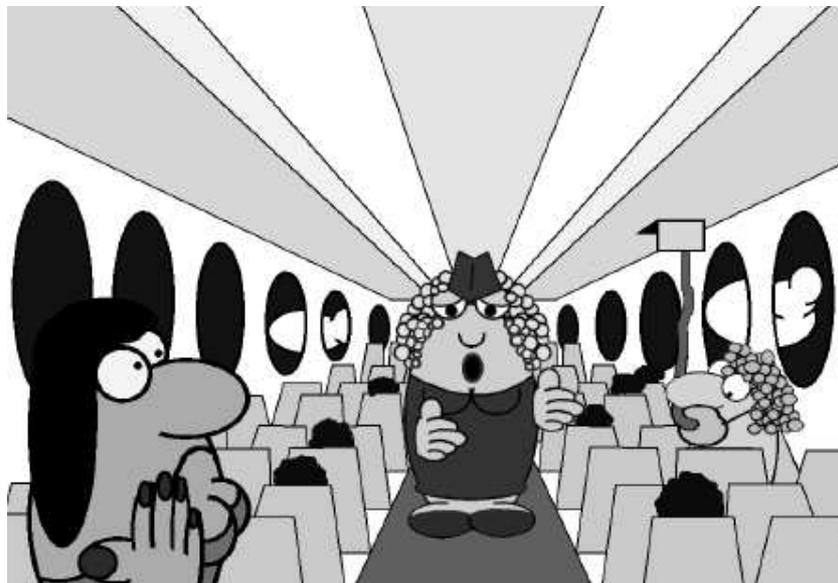
Welcome to Our May 2013 Newsletter



A Note from Alex: Well this month is a busy month for ME as it is International ME Awareness Day on Sunday 12th May 2013. This is its 21st anniversary! Also this month every single member will receive a paper copy of this months news letter, as we have sent you out what we think is a very helpful contacts booklet. Thanks to Tracy's hard work in putting it together for us. Along with this you will also find a letter from Caroline.

For once I don't have much to say and hope you enjoy reading all that we have included, and for our members that receive their newsletter via email

service will be back to normal next month.



Don't Panic! We don't have a severe technical problem. This lady with CFS just needs some oxygen..

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

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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.

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 16th May: Lucy and Heather, Neuro-physiotherapists, will talk about the hydrotherapy pilots we took part in, along with others with neurological conditions, between August 2012 and January 2013, and show some very embarrassing slides of some of us in the pool.

Thursday 20th June: Staff from the local Millercare shop will give a talk about various aids and equipment. If anyone has anything in particular they would like them to cover, please let me know (as soon as you can e-mail maria@mesupportgroup.co.uk or Tel: 01204 575613). Thanks Maria.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 13th May at 2pm, at The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY.** It has plenty of parking, good accessibility, comfortable seating and is relatively quiet. They serve 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. We usually meet at the oval table next to the bar.

Prestwich Socials: We meet informally on the second Wednesday of each month, our next will be on **Wednesday 8th May at 2pm, at The Orange Tree, Fairfax Road, Prestwich, M25 1AS.** Everyone and their carers are welcome and we'll put a newsletter on the table so you can find us.

Yoga Classes: Are **3:00pm-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. **Our yoga classes are currently being funded by the Comic Relief/Community Fund.**

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.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

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



**Supported by:
Health for Bolton and the
Big Bolton Fund via Bolton CVS**



Funding Bolton's future

Bury/Bolton ME/CFS Support Group Social Updates

After a successful trial run, we are now holding informal socials in Prestwich on the second Wednesday of every month, 2pm, at The Orange Tree, Fairfax Road, Prestwich, M25 1AS.

We will still be holding the Radcliffe social at the Sparking Clog, but from June we will also be changing the day on which we meet to the first Wednesday of the month, as we have to keep moving the day to avoid the Bank Holidays and it confuses all of us. Below are the dates of the next two socials: **Radcliffe Monday 13th May & Wednesday 5th June. Prestwich Wednesday 8th May & Wednesday 12th June.** For all of the usual activities please see page 2.

Greater Manchester Neurological Alliance

The GMNA is holding a meeting on Friday 17th May 2013 from 12.30-4:00pm at Salford Innovation Forum, Frederick Road, Salford M6 6FP. People will share information about changes in the NHS and will focus on the services provided by groups like ourselves. The committee cannot attend as we have other meetings that week. **We would really like someone and/or their carer to represent the group** to make sure we are acknowledged as a neurological condition and to keep them aware of our work. People from other support groups will be there so you can tell them about M.E and how badly we need the NHS to provide for us. You don't have to stay for all the meeting. Please let us know if you think you can attend by contacting Caroline: Tel: 01204 525 955 or Email: caroline@mesupportgroup.co.uk.

ETAG

NHS Bolton, in partnership with Bolton CVS has set up an Equality Target Action Group Network (ETAG). They recognise that people experience discrimination and unfair treatment because of their age, caring responsibilities, disability, etc. They aim to improve this by working with patients and service providers to identify issues relating to health concerns or barriers to services, hold managers to account, identifying training needs, etc. If you don't say what the problems are, they can't fix them! Please email or write to me with your thoughts on these:

- **Barriers to health care:** They want to know what barriers you experience when trying to access services? These can be physical, e.g. nowhere to park, or too far to walk into the building, etc. They can also be things like not having an interpreter if you are deaf, or not being referred elsewhere because your doctor doesn't believe in ME!
- **Out of hours services:** How can they improve them? How can they make it easier for you to get health care out of office hours? Would you talk to a doctor on Skype, for example? What would encourage you to use the service more? Where should they be based? In one central building in town, or 4 smaller buildings around the borough so that it is easier for people from different areas to access, etc? Give us your ideas, they want to know!

Email: caroline@mesupportgroup.co.uk

Launch of the UK CFS/ME Research Collaborative.

By the CFS Research Foundation.

A new group to galvanize research into CFS/ME was launched in London yesterday (April 22nd 2013). Called the UK CFS/ME Research Collaborative (UK CMRC), the group will pull together researchers and scientists, funding charities and trusts as well as support groups for the first time ever.

The new UK-wide research group's aim is to greatly advance understanding and treatment into CFS/ME. The country's leading scientists and researchers in CFS/ME have signed up to the group, whose chairman is Professor Stephen Holgate CBE, MRC Professor of Immunopharmacology at the University of Southampton.

The CFS Research Foundation is a founder member of UK CMRC. Anne Faulkner, the Foundation's Honorary Director, said: "The Foundation welcomes the Collaborative wholeheartedly. We have been frustrated by not being able to widen our research. Now research will go forward on a wide front."

The launch of the UK CMRC was attended by around one hundred and fifty scientists and researchers as well as representatives from funding and patient support charities and the UK's major research funders including the Medical Research Council (MRC), the NHS National Institute for Health Research and the Wellcome Trust.

The Foundation looks forward to exciting and novel research ideas coming from the UK CMRC. As one of our valued supporters we want to reassure you that your generous donations will stay within the Foundation and only go towards research studies the Foundation has agreed to fund.

Our important, three year study into pain will get underway soon and we hope to be able to announce details of another wide ranging study later this year.

In the meantime, thank you for your continuing and generous support without which our work could not go forward.

If you have any questions about the new group, or any other matter relating to the Foundation or its research work, please don't hesitate to get in touch with us at info@cfsrf.org.uk or call us on 01923 268641 between 10am and 1pm weekdays.

Thank You

I would like to say a really big thank you to everybody who made my retirement from the Support Group such a memorable occasion. Those of you who were at the AGM would have seen my surprise and emotion at the wonderful cash gift, garden planter and beautiful cards that were given to me. I'm not often not at a loss for words but words failed me on that occasion! I have already earmarked some of the money for new cushions to go with my new lounge suite, so I will have a constant reminder of the Group when I have my feet up! I have made many good friends over the years and will always value their friendship. I wish the Group and the committee well for the future and I am sure you will be successful in building on the ME Services and support for each other we have achieved. Love Yvonne.

Woman of the Year.

We are delighted to tell you that our super-star volunteer and co-founder Yvonne Leech has been named as a finalist for Woman of the Year in The Fusion Awards! The awards are a celebration of the achievements in the community and give recognition to those who take part in so much community work, but do not always remain in the public domain. Yvonne has worked immensely hard for the group for three decades, fighting to get recognition for our illness and support our carers. The awards are June 1st, so we will let you know the outcome then. Fingers crossed!

Do you have any Old Newsletter and Press Articles?

I think it would be nice to keep a record of all the group's work and achievements, so I'm looking for the earlier versions of the newsletter that you may have stashed in a cupboard somewhere? I have computer versions going back to 2006, but would like older ones please. I know Bolton Archives have them, but it would be nice to have our own copies as well. I am also looking for any old press clippings about the group or ME clinic, so if you have any, please send them my way! Caroline Higson, 53 Denstone Crescent, Harwood, Bolton, BL2 5DE, or
Email: caroline@mesupportgroup.co.uk

ME Friendly Health Professionals Directory

Many members ask if we know of any GPs or consultants (such as neurologists, etc) who are sympathetic to ME or helpful. If you do know of any health professionals (NHS or private) who are especially understanding, or good for writing reports, please let us know. We would like to start a directory of helpful professionals, in case anyone in the same area enquires. Email caroline@mesupportgroup.co.uk or phone 01204 525 955 if you know of one, or are looking for one.

Local Welfare Provision with Bolton Council

From 1st April 2013 the Council may be able to help vulnerable customers living in Bolton by providing subsistence or financial support in the event they have a short term immediate need.

Support will take the form of goods and services and will be designed to provide customers with the following:

- Food packages
- Basic white goods and basic household furniture
- Help with travel costs
- Help with fuel costs

It is important to note that support will not be provided in the form of cash payments.

Customers can make a claim for Local Welfare Provision either online or by telephone. The hotline number and internet link are as follows:

Hotline Tel: 01204 332772

Link: <http://moss.bolton.gov.uk/contactus/Pages/Doitonline.aspx>

Information about the Council's access points where customers can access a free telephone line and/or free internet access can be found below.

Access Bolton, Town Hall, Bolton

Mon – Fri 8.30 – 5.30

Saturday 9.00 – 1.00

Blackrod Town Council

Mon and Thurs 9.15 – 4.30 (closed for lunch 12.30-1.30)

Horwich Library

Mon – Thurs 9.00 – 5.00 (closed for lunch 12.30-1.30)

Wednesday (closed for lunch 12.00-1.00)

Fri – 9.00 – 12.30

Westhoughton Town Hall (Internet/self-serve unavailable here)

Mon – Fri 9.00 – 5.00 (closed for lunch 12.30-1.30)

Little Lever Library

Wed – 09.00-5.00 (closed for lunch 12.30-1.30)

To find out the opening times of your local library go to the Council website and click on Libraries or ring the Library enquiry line on 01204 333173.

Bolton at Home Ltd Community Offices:

Deane, Ucan Centre 338 000

Great Lever - Phone 335588

Withins - Phone 335615

Tonge Moor - Phone 335296

Other Access Points (Internet Access available):

Blackrod Library

Bromley Cross Library

Brightmet Health Centre

Castle Hill Centre

Central Library

Harwood Library

Heaton Library

High Street Library

Horwich Library

Little Lever Library

Westhoughton Library

Nom De Plume. A family Recipe

I have to confess, I don't like terms such as fusion, as a means of describing food. It sounds faddy and too crude to sustain any lasting interest of mine. The few times I have entertained notion of curiosity, attempts by restaurateurs to convince me otherwise, have ultimately failed.

Such alchemy is hard, harder still when dealing with an ever demanding and discerning clientele, who not only require a meal but an experience too.

Now declared, such prejudice seems silly, mean minded even, particularly as we are all a fusion of some kind or other. In fact, I don't need to look far into my own heritage, to see the wonderful mix of cultural diversity that has led me to become me. Or indeed, to the food I cook and eat.

But home cooking, is an altogether different beast than commercial food.

It has the possibility to play with the nuance of authenticity that restaurants rarely are able to convey. From the ingredients we use, to the manner in which we use them, each shared plateful of food, can delicately illustrate a life of experience and travel, one has had the privilege to have. From the sturdy banana leaved parcels we used in East Africa, to steam and serve our green bananas from; to piles of Asian deep fried, neon orange, filigree battered sweets, steeped in cardamon syrup; I have witnessed and tasted many things that now form part of my own repertoire. These dishes tangibly trace and fuse the memories and encounters that my words could never really do justice to. But I believe there to be grace in trying, as much as there is in sharing.

My family and I emigrated to East Africa in the early part of the nineteen eighties. My parents looked to this land with a longing and romanticism they'd encountered when they lived there as newly weds. For me it was a place of extremes. It was too buoyant, too hot, too bright, too loud, too dangerous, and far too unpredictable for my sensibilities to endure. So instead of fulfilment, I felt robbed of the minute traces of stability I'd tried desperately to hold together. And in so doing, the country heightened the sense of alienation my nine year old self felt. But I wonder... Is it churlish to dismiss all of those years away..? Perhaps the adult in me should begin to find some kind of resolution, some sense of purpose to it all... Maybe a strong bonding agent, strong enough to help fuse the very few good bits I have together.

And so it is in this spirit that I share this much loved recipe with you. It is one that my family inherited, and at least to my mind, is a perfect fusion of British comfort food, exotic Asian spice, and just enough eccentricity to belong to my family and the many generations of excursionists who inhabit it.

Ingredients you will need:

This recipe is to feed two adults, but I leave it up to you to reshape and modify, so that it might reflect the appetites and fancies of your eaters.

- 3 large Organic Maris piper or King Edward potatoes (*In truth most potatoes will do, but it is advised to opt for a type that will crisp on the outside whilst being fluffy on the inside*)
- 900 mls of organic rapeseed/sunflower oil
- 1 tablespoon of organic rapeseed/sunflower oil
- 1 large organic brown onion (*finely chopped*)
- 1 inch of fresh ginger
- 3 segments of smoked or fresh garlic
- 1 teaspoon of organic turmeric powder
- A generous pinch of flaked, organic smoked sea salt
- The skin of a moderately hot green chilly
- 1 large can of organic tinned tomatoes (*chopped*)
- 300 mls of filtered/still mineral water
- 1/2 an un-waxed organic lemon and its zest
- 1/2 a generous bunch of organic Coriander (*finely chop the fresh Coriander, which will be the last ingredient to be used*)

A spice mix made from:

- 1 teaspoon of Coriander seeds,
- 1 teaspoon of Cinnamon bark
- 1 teaspoon of lime powder
- 1 teaspoon of cumin
- 1 teaspoon of cloves & whole black pepper corns

Method:

The Sauce

Prepare the spices, which provide a depth of authentic eastern flavour that makes this dish so distinctive.

1. In a dry hot frying pan toast all five spices together, until they release their aroma and begin to spit.
2. Remove the pan from its heat, and allow the mix to cool completely.

3. Grind finely, either by using a mortar and pestle or coffee grinder.
4. Combine the blend with the turmeric chilli, and zest of the lemon (better done before slicing in half, to squeeze away its juice)
5. Pound the peeled garlic and ginger into a textured paste, adding the flaked salt to act as an abrasive.
6. Pour the minor amount of sunflower and rapeseed oil into a saucepan, heat until moderately hot. Add the chopped onion and cook until very brown. In so doing, the onion's natural sugars are exchanged for a deep flavour which acts as the back bone to most Middle Eastern and Asian cooking. Settling for a moderately cooked onion will produce too much sweetness, so it is important not to rush this stage.
7. Using a wooden spoon add the spice mix in, and stir continually for a few minutes. Once the ingredients have become acquainted and the spices have begun to spit and release their aroma again, take the pan off the heat to conserve the flavour. Spices are prone to burning and then turning bitter so be warned. Next, stir the ginger and garlic into the pan, which has now been returned to the hob. A few moments later pour into this, the tinned chopped tomatoes, lemon zest and water. Put the lid on, reduce the heat to its minimal setting, and cook the sauce until the bright pillar box red has been replaced by a deep dark maroon.
8. This will take 35 to 45 minutes depending on the capability of your hob.

As a general rule, gas hobs and copper pans conduct heat the best. As cooked spices mature and deepen with time, one can either make this stage of the dish, a day in advance or once fully cooled can even be frozen. At any rate, when intended to serve, heat the sauce until warm.

The Potatoes:

1. Now soak the chipped potatoes for as long as it takes your salted boiling water to cool, then drain and leave to one side.
2. Gingerly pour the larger quantity of oil into a deep frying pan. Heat until the oil is at an appropriate temperature to fry the chipped potatoes.
3. Generally speaking it is best to fry the potatoes for 5 minutes on a maximum setting, which is then reduced to a moderate temperature to ensure the chips are crispy on the outside whilst being fully cooked throughout.
4. While this is happening, add the juice of the lemon to the sauce. Once the chips have been removed and drained of any excess oil, combine them with the sauce. Garnish liberally with fresh coriander. To eat as a snack or serve with fish cakes, a fried egg or crunchy salad.

JANE COLBY'S RECORDED PRESENTATION

From the Tymes Trust. For schools, parents, Local Authorities

Just 25 minutes long, this talk with 10 slides shows how the Department for Education's new statutory guideline helps children with ME.

http://www.nisai.com/Articles/350386/Nisai/News/Jane_Colby_on.aspx

ME can be so severe and chronic that the education system has great difficulty in coping with it. As a Head Teacher I learned that the best thing to do, is just to do what works. And that will be different in different cases - but it must comply with this new government guideline, and that's what my talk explains. It is significantly different from its predecessor (the 'Access to Education' guideline).

I start with a look at the title: 'Ensuring a good education for children who cannot attend school because of health needs'. The Department states that this 'applies equally, whether a child cannot attend school at all or can only attend intermittently.'

It applies to children in all types of school, free schools, academies, state schools, private schools, and those who are not on the roll of a school. It's the Local Authority's responsibility to ensure that these children get a 'good' education.

The whole guideline is based on the question of what's best for each individual child. In my emails and phone calls with the Department, they have said to me that they really do want the child to

know that: 'It is not their fault'. They are ill. It is so easy for a child to feel a failure when actually it's the system that is failing them.

Remember, a keynote of the guidance is that there must be *no blanket policies* for any particular health condition, nothing inflexible, no lists of what will and won't be done for any specific condition. That's one of the 'should not's'.

I have taken care to examine the growing controversy of hospitals 'prescribing' graded attendance programmes which schools and tutors often feel they must follow, despite families telling us they have become a focus for conflict between them and the school. Such programmes that I have so far come across have run contrary to several aspects of this new statutory education guideline. In this talk, I explain why. It is important that in liaising with medical professionals, education professionals do not abdicate their own role.

Disability and equality legislation is also relevant. ME involves disability within the brain, something I discuss in my talk, and we must not be guilty of discrimination. It takes time and energy to heal, together with sufficient recuperation, and because there is no cure, the National Institute for Clinical Excellence makes it clear that no treatment of any sort need be accepted. I understand that some schools have erroneously believed that the family must accept a hospital's management programme for their child, which is clearly contrary to NICE.

To go back to the key point of this guideline; everything must be done to address the child's individual needs, rather than impose some blanket policy or programme. But there are many practical ways of doing this, and really much of it is down to common sense and building trust and good relationships. And, of course, modern technology and virtual education are becoming very successful and an excellent alternative or adjunct to other forms of education. In that connection, I must thank the Nisai Virtual Academy for enabling me to make this presentation and for hosting the webinar on which it is based.

Without going into lots of medical detail, I do touch on the problem of the different terminology (ME and CFS) so that any school listening to the talk understands that they need to play safe, because of the potential for relapse in cases of ME, under whatever name.

So now it only remains for you to click on the above link! There should be something there to help everyone and this is a tool you can send around to others. The link to the guideline itself is also there, if you wish to read it after listening.

PIP and the Motability Scheme. by Alex

I don't know about any of you but with the changes that have already started with transferring DLA claimants to the new PIP. I have been worrying about how long I will be waiting until it's my turn to be transfer to PIP and even if I'll still get the higher rate which pays for my Motability scheme car. So I was glad to see the following information on their website, as I was worried that if and when I get transferred could I end up having to pay the lease payments out of my own pocket as like most of us we are struggling to keep our heads above water, which is becoming harder as the economy just isn't bouncing back yet and every bill we receive or shopping trip costs us more.

The Motability Scheme will be working with PIP in the same way as it does with DLA. Motability will be continuing to lease cars, powered wheelchairs and scooters to disabled people who receive either:

- The Higher Rate Mobility Component of DLA
- The Enhanced Rate of the Mobility Component of PIP (from April 2013) which will have the same value as the Higher Rate Mobility Component of DLA.
- The War Pensioners' Mobility Supplement

If you are an existing DLA recipient who is awarded the Enhanced Rate of the Mobility Component of PIP, then your Motability lease will continue as you move from DLA to PIP.

If you are an existing DLA recipient who has not received the Enhanced Rate of the Mobility Component of PIP, you will not be eligible to use the Motability Scheme.

If this happens:

- The leasing agreement will end
- Motability will arrange with you for the vehicle to be returned

- Motability refunds any Advance Payment on a pro-rata basis e.g. if the agreement ended after one year of a three year lease, two-thirds of the Advance Payment would be refunded
- Subject to terms and conditions, Motability may in some cases be able to offer the vehicle for sale to you
- You will not be liable for any early termination penalties or administration charges

Finding out about the above these key facts has made me feel much better and I hope it does the same for other members who are on the Motability scheme, as I said above we can't afford any extra bill. If you want to read more about the Motability Scheme and the PIP changes please go to: <http://www.motability.co.uk/about-us/news-and-information/personal-independence-payment>

Late Edition

Here's a brief roundup of some of the recent articles covering CFS/ME during April.

The UK CFS/ME Research Collaborative (UK CMRC) was launched on the 22nd April. It's bringing together a wide group of experts who are aiming to get a better understanding of the condition through research. At the same time, 3 research projects were announced. The first involves examining whether Rituximab, could be used as a medicine in order to understand more about fatigue mechanisms. The second trial will explore why people with CFS/ME have low blood pressure and whether this could be a target for treatment. The third study explores the role inflammation might play in the symptoms of fatigue. - **Source: You and ME: working together to discover biological causes of CFS/ME – Health Canal – 23 April**

At the same launch, Scientists announced that CFS/ME patients use additional brain regions to do simple tasks requiring attention. This may explain the problems many sufferers have with memory. They also announced that they had found abnormalities in the muscle cells of CFS/ME sufferers. Their cells produced on average 20 times more acid when exercised, suggesting a cause for the aching muscles some patients report as soon as they begin to exercise.

Changes to benefits and council tax relief mean that Peter Boor, 57, of Penzance, who lost his job because of M.E., has had to halve the £50 a month he previously spent on food. "I haven't had a cooked meal for nearly a week because I can't afford it," he says. "It's criminal." – **Source: Little money left for food – The Cornishman 2 April**

The authoress, a sufferer of 7 years shares the variety of techniques, supplements and treatments to help her feel better. Examples, include, milk thistle, L-Carnitine, TENS Unit, Epsom salts bath and pacing. - **Tools for Fighting Fibromyalgia & Chronic Fatigue Syndrome: What's in Your Toolbox** – About.com Apr 23

A recent study of 834 patients looked at their state of health before and after they were referred to a specialist NHS CFS/ME clinic. It found that patients who attend NHS specialist CFS/ME services can expect similar improvements in fatigue, anxiety and depression to participants receiving cognitive behavioural therapy and graded exercise therapy in a recent trial, but are likely to experience less improvement in physical function. Outcomes were predicted by fatigue, disability and pain at assessment. **Source: Treatment outcome in adults with chronic fatigue syndrome: a prospective study in England based on the CFS/ME National Outcomes Database – ProHealth - April 2**

Dr Dan Peterson was researching the effect of Vistide on a group of 65 severely ill CFS/ME patients who were also infected with the Herpes virus. He found that the antiviral can have dramatic effects on functional capacity in these patients. - **Source: Antiviral (Vistide) Effective in Treating Herpes virus Infected Chronic Fatigue Syndrome (ME/CFS) Patients – ProHealth – April 9**

Contact List Additions/Amendments.

Since April there have already been several changes to some of the organisations listed!

If you find any other listings have changed, or you find other organisations helpful, please contact Tracy on 01204 592 226 and we will try to keep the list as relevant & up-to-date as possible. Many thanks.

On p3-4 Councils

It has been suggested that it is often useful to **try either Bury or Bolton Carers with a problem** (before trying the council), as they are good at pointing you in the right direction. If you ring the council numbers it may be harder to access the correct information unless you know which department you need. It may therefore be worth adding the following Carer numbers to the top of pages 3-4 for reference:

Bolton Carers Support: Tel: 01204 363056 www.boltoncarersupport.org.uk
Email: boltoncarers@btconnect.com

Bury Carers Centre: is the 1-stop-shop advice number for Bury covering issues such as Outreach/Advocacy support/Carers Rights/access to benefits advice and more.

Princess Royal Trust Bury Carers Centre: Tel: 0161 763 4867 www.burycarerscentre.com
Email: burycarers@yahoo.co.uk Victoria Buildings, 9, Silver St. Bury

Bury Young Carers: Tel: 0161 253 6902/5144 Email: buryyoungcarers@bury.gov.uk

NHS Services Section

Page 11 Bolton CCG: has a new website although the phone no is currently the same.
www.boltonccg.nhs.uk

Bury PCT is currently still available through the original PCT website/phone no. Please let me know if this changes.

Page 12 Bury PALS: The number listed in the Contact sheet Tel: 0800 328 3166 is a general info point. Although it will still work, their new number is Tel: 0161 212 6270, also available through the PCT website. Email: patientservices.gmcscu@nhs.net

Page 13 The Manchester CFS/ME Service for Children & Young People: Tel: 0161 701 4516
Co-ordinating Clinician for Bury Children's Service is Alex Woore Email: Alex.woore@cmft.nhs.uk

Page 13 Salford Royal NHS Foundation Trust CFS Service: Clinical Lead is Dr. Annice Mukherjee

Transport & Practical Help Section

Page 17 Unfortunately in April **Bury Handy Person Scheme** lost funding & is no longer available.

Bury Age UK Handyman Scheme: available for those over 60 but this may be more expensive.
Tel: 0161 763 9030 www.ageuk.org.uk/bury/our-services/handyperson-service

Bolton Age UK Handyman Service: Tel: 01204 382411
www.ageuk.org.uk/bolton/our-services/handyman-service

Local Support Groups Section

Page 22 Bolton Fibromyalgia Group: is relocating to Swinton. The Hidden Disability Group
Contact Tel: 0161 728 8106. Meetings at Unit 10, Junction Eco Park, Rake Lane, Clifton. M27 8LR

Additions:

Crossroads: Charity offering practical & emotional support for carers incl. personal care of patients & respite packages.

Bolton Crossroads: office Tel: 01204 365025 Email: Bolton@gmcrossroads.co.uk

Bury Crossroads: office Tel: 0161 763 4163 Email: www.crossroadscarebury.org.uk

For **info on VAT relief** available on certain building work, equipment, and vehicles for the disabled follow this link. <http://www.hmrc.gov.uk/vat/sectors/consumers/disabled.htm>