

Welcome to Our March 2013

Newsletter



A Note from Alex: This month's newsletter is cram packed with some very interesting articles, especially the write up for our Longsight social where Gail Sumner gave a very interesting talk about nutrition and the Perrins clinic and trials.

We also have updates on the METRIC study, ESA appeal nightmares and hopefully some important information on Bedroom Tax which may help those of you who will be affected by this.

Lastly please don't forget that on the 21st March it's our AGM and if you are unable to attend please make sure that you post or email your ballot paper. We

look forward to seeing as many of you who are able to attend the AGM, and just to remind you that after the AGM we will have a raffle and our usual social.



What they're doing is discussing whether it should be called CFS or ME!

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 21st March - AGM. We would appreciate it, if as many of you can attend the AGM in order to show support for the committee and our support group in general. The AGM should last about an hour at the most. Don't forget that after the AGM we will have our usual social and we will also be holding a raffle.

Please note that there will be no meeting in April.

Radcliffe Socials: We meet informally on the first Monday of each month, our next will be on **Monday 8th April** at **the new time of 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.

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 Meeting

February 2013. by Caroline

For our February meeting, Gail Sumner kindly came to talk to us. The meeting was very well attended with around 45 people coming to hear Gail give her third talk to our group, which are always well received.

Gail started by telling us about her background. She is a fully chartered and state registered physiotherapist who specialises in ME/CFS, and is the Perrin™ Technique practitioner for Bolton. She runs clinics in Bolton, Westhoughton and Prestwich, as well as doing home visits. Gail was diagnosed with ME 13 years ago.

She started by explaining about Dr Perrin's new research, and the potential benefits it could have, if successful.

Dr Perrin's research is in conjunction with the NHS, and will consist of Gail, and another osteopath trained in the Perrin Technique™, diagnosing ME/CFS using his methods. Full details can be found here: <http://www.theperrinclinic.com/2013.pdf>.

The Perrin Technique™ is based on Dr Perrin's theory that different stresses on the body lead to overstrain of the sympathetic nervous system from a build up of toxins in the lymphatic fluid around the brain and spinal cord. Dr Perrin believes that this poisons the body and brain, impairing their normal functioning. His technique involves massaging the head, neck, back, and chest to move toxins out of the lymphatic system, into the bloodstream so that the liver can detoxify them. Symptoms should improve once the toxins have been removed and the brain and sympathetic nervous system can function properly. Further details can be found at www.theperrinclinic.com.

This research is being entirely self-funded, and £60,000 has to be raised in order for the research project to go ahead. There are a number of fund raising projects taking place for this through the F.O.R.M.E. charity see www.forme-cfs.co.uk if you would like to simply register your support or assist in fund raising.

For the research, people with ME/CFS and people who do not have the condition (carer, friend, etc, but not a blood relative) are examined, and the practitioners must declare which one has ME/CFS purely from a 10 minute physical examination. (If you would like to be part of this research, please see page 9). If the research is successful, it would mean a diagnosis could be made a lot quicker, as opposed to the months, or even years, that people are waiting now. A patient who sees their GP after 4-6 weeks of being unwell could be quickly assessed as to whether it could be ME/CFS and refer them on, shortening the intervention time. This physical exam would not cost anything, as there are no blood tests, scans, consults, etc.

Gail then told us about the busy year she's had. In addition to seeing her own patients, she has attended several conferences, observed Dr Sarah Myhill with her patients and also qualified as a nutritional therapist! There are many theories about the cause of ME/CFS, which she says all have merit, but they are often based on one theory alone being correct, such as germ theory, methylation cycle block, oxidative stress, or mitochondrial dysfunction.

Gail improved when she looked at the bigger picture, not just at test results. People with the condition who get better often use a combined approach of methods, not just one.

She then explained the "Integral Model of Health" to us, when applied to ME/CFS.

This looks at 4 areas:

- **Building psychological, emotional and spiritual resilience**, e.g. by looking at energy-depleting personality types, such as perfectionists, or by addressing unresolved trauma.
- **Building emotional and cultural support**, such as battling the stigma of the illness being "unreal" or addressing lack of understanding from friends, family and work.
- **Building biochemical, physical and structural resilience** by looking at the endocrine system, metabolic imbalances, infections, intolerances, sleep, medications, pacing, supplements, diet, etc.
- **Building social and economic support**, as NHS treatment is often unhelpful and alternative methods can be costly. Getting access to a support group is also important.

These address stresses on the body. When over-stimulated, the body is in a state of stress. Gail initially thought the fact she couldn't "switch off" was not important, but later came to realise that it was. She received little help from conventional medicine and the illness came with stigma and no validation of her symptoms. Gail spent 5 years focussing on what was wrong inside the cells, e.g. with blood tests and scans. However, the health assessment doesn't end there; it is certainly important, but only part of a bigger picture. It was only when other factors were taken into consideration that her health improved.

February Meeting 2013 Cont ...

At the Biocare ME/CFS Conference 2012, Dr Sarah Myhill had recommendations that everyone with ME/CFS should follow, but it's always best to seek professional advice where possible. Gail shared these with us:

1. Diet: This can be changed and not at too great a cost. Diet is a hugely important tool in recovery, as the bodies first defence is in the nutrients obtained from food. Unfortunately the Western diet contains lots of food which can lead to "leaky gut"-a condition where the walls of the gut are damaged and allow large food molecules, antigens and toxins to enter the bloodstream, where they cause an immune reaction and place a heavy burden on the liver. The only way to repair the gut wall is to remove the offending foods. For this, Dr Myhill advocates the Stone Age Diet, which is centred on protein, fat and vegetable fibre. The diet avoids common allergens (yeast, grains, dairy and gluten) as much as possible, helping prevent fermentation in the gut and aiding the digestion and absorption of food. From <http://www.drmyhill.co.uk>

Allowed food and drinks:

- Any meats: Fatty meat is ideal
- Eggs - an excellent source of lecithin (eat soft yolks).
- Any fish: salmon, mackerel, cod, haddock (care with smoked fish which often contains dyes). Tinned fish in brine or olive oil is fine. Tinned shrimps, prawns, mussels, cockles etc.
- Any green vegetables and all salads.
- French dressing, cold pressed nut and seed oils, spices and herbs, and reduced sodium sea salt,
- Fermented foods-sauerkraut, kefir, etc.
- Bottled or filtered water, herbal and redbush teas.
- Tea and coffee in moderation are fine so long as caffeine is tolerated
- Dark chocolate (at least 70% cocoa solids), berries, seeds, nuts, pulses, oats and oatcakes are very low in carbohydrates. Initially avoid them and see how you tolerate them later on.

Avoid:

- Fruit:- It is high in sugar in the form of fructose, which is readily fermented. In some people this interferes with the mechanism by which the liver corrects low blood sugar thereby making this problem very much worse.
- All other foods are forbidden:- This means no tap water, alcohol, all grains including wheat (bread, biscuit, cake, pasta, pastry), rye, corn, rice, millet, dairy products (milk, butter, cheese, yoghurt, dried milk), vinegar and sugar. Avoid high carbohydrate vegetables such as potato, sweet potato, parsnip and Swede.

2. Patients should take comprehensive multi-vitamin and multi-mineral supplements.

3. A good quality essential fatty acid supplement should be taken.

4. Additional vitamin C supplements should be taken.

5. Patients should consider vitamin D supplementation. Sunlight is a preferable source, but is rarely strong enough in the UK to maintain levels, and dairy products are a poor source of vitamin D. We should all be taking 2,000 i.u. vitamin D daily.

6. Consider transdermal (skin) application of supplements, e.g. in gel or spray form to bypass the gut and aid absorption. NB; Epsom salts are a good way to increase magnesium levels, but must be introduced slowly due to sulphate in the salts stimulating liver detoxification pathways.

As mentioned above, Gail has recently qualified as a nutritional therapist and shared some more tips to help ME/CFS symptoms, most of the food recommendations don't cost a lot to do:

- Seek advice from a BANT registered nutritional therapist where possible, ideally one who specialises in the condition.
- Keep a food diary (what you've eaten and drank, along with how you feel physically and emotionally), in order to identify possible intolerances. Wheat and dairy are the most common.
- Consider metabolic typing tests to determine the best eating plan for you, fast oxidiser, slow oxidiser or balanced type.
- Eat more anti-inflammatory foods, nuts and seeds, fats, coconut water, antioxidants, herbs and spices (garlic, ginger, turmeric and cinnamon), berries, flax-seeds, eggs, oily fish, olives, etc.
- Balance blood sugar (see next page)

February Meeting 2013 Cont ...

Blood Sugar:

Unbalanced blood sugar levels cause energy levels to quickly rise and crash, resulting in fatigue. Beyond this, it also stresses the body and causes oxidative damage to cells and adrenal glands (our “back up” energy system).

Always eat breakfast: Your body needs fuel to work, just like a car does. Avoid coffee without food.

Eat 3 smaller meals and 2 snacks each day: Eating every 3-4 hours helps prevent blood sugar drops and the subsequent risk of overeating, which spikes blood sugar.

Include high quality protein with every meal and snack: Protein slows the release of energy from food, keeping you fuller for longer. Pineapple and papaya consumed with or after food will aid protein digestion, easing digestive symptoms. Protein is good for detoxing and is also needed for the repair of cells, which are made of fat and protein.

Avoid refined carbohydrates and sugars: White rice, white bread and white pasta release their energy quickly causing blood sugar highs and lows. Complex carbohydrates will release energy more slowly, such as; whole grains (brown rice, quinoa, buckwheat, oats and rye).

Limit all stimulants: Alcohols, high sugar drinks, coffee and chocolate increase blood sugar. If consumed, don't take on an empty stomach.

Don't skip meals: This causes a big drop in blood sugar levels, causing food cravings. You then reach for the first sugary thing you see, which makes blood sugar levels spike!

Increase your intake of low GI foods: Berries, barley, quinoa, bulgar, pulses, beans, lentils, nuts (almonds, walnuts, soy nuts) oats and unsweetened natural yogurt.

Limit or avoid high GI foods: These foods cause a spike in blood sugar levels, which increase carbohydrate cravings, and can increase overall appetite, leading to overeating. Examples include; chocolate, cakes, juices with added sugar, many breakfast cereals, sugar, sweetened fizzy drinks, white bread and pasta.

Drink 2 litres of water per day: Away from meals and sipped slowly to avoid stress on the kidneys. Try diluted fresh fruit juices, organic vegetable juices and herbal teas.

It's also important to identify areas of stress: -Adopt more effective time management to allow time for relaxation and enjoyment. Consider tai chi, qigong, breathing techniques, or yoga (thanks to Bolton CVS, we run free classes, every Tuesday from 3pm-4:15pm at the Jubilee Centre, Bolton!)

Gail said that following this diet advice meant she'd got to try things she'd never thought she'd eat! She emphasised that it's alright to have fun and indulge once in a while (as long as you still avoid things you're definitely intolerant to!) and to not beat yourself up about it. Get back “on the wagon” as soon as you can. Follow the 80/20 rule-good stuff 80% of the time, and a treat for 20% of the time! As a general principle - breakfast like an emperor, lunch like a king, supper like a pauper!

Other ME/CFS practitioners, such as Niki Gratrix, believe the role of lectins is really important, and whilst the diet may not be easy, huge benefits can be found:

Lectins are substances/molecules in some grains and vegetables which can further damage the gut wall and interfere with its repair. There are no tests for lectin sensitivity, so removal from the diet is the only way to see if they contribute to your symptoms. The main lectin containing food groups are, dairy, grains, the nightshade family and legumes. Including foods such as; wheat, tomato, beans, cereal grains, seeds, nuts, and potatoes.

4 areas to consider for chronic fatigue management are:

Structural work: Breathing exercises, stretching, and hands on structural work, to get joints moving and the circulatory and lymphatic systems working.

Diet: You don't need lots of expensive supplements, some of them will pass through the body and make expensive urine if digestion and absorption is poor, get goodness from food! It can make a big difference if done well.

Stress: Change areas of your life to reduce or remove stress where possible. Where you can't, learn new coping mechanisms to help. Also work on retraining dominant thought patterns that prevent the mind from switching off, thereby stopping the body healing and repairing.

Geopathic & electromagnetic stress: The body is sensitive to the environment - light, noise, sound, etc, but there are ways to reduce this (see next page).

February Meeting 2013 Cont ...

Geopathic stress is natural radiation that comes up from the earth and is altered by weak electromagnetic fields, causing a number of health conditions. When we are asleep, our body repairs itself. In areas of geopathic stress, the body uses its energy only to keep vital organs functioning, compromising our immune system.

There are ways to lessen the effects of this, such as turning your wi-fi off at night or buy grounding sheets for your bed to reflect EMF sources, (such as wifi or cordless phones), priced from around £70 for a single to £120 for king size. Gail's patients have seen improvements with these, and their partners also say they sleep better! They are good for inflammation and pain and may be worth considering. Visit www.royriggs.co.uk for more info.

Gail has a number of handouts explaining these in more depth. If you would like copies emailed to you (saves us funds) or printed out if you don't have access to a computer, please email caroline@mesupportgroup.co.uk, or phone 01204 525 955.

Gail can be contacted via: gail@backtohealthphysio.com or via her website:

<http://www.backtohealthphysio.com> For enquiries and home visits, phone: 07976 915314

There are two Lancashire based clinics, one in Deansgate Osteopathic & Physiotherapy Clinic, Bolton (01204 522133) and one in Markland Therapy Centre, Westhoughton (01942 841088). She also works at the Perrin Clinic in Prestwich: 0161 773 0123

An Update from the METRIC Team:

by Lisa Riste, METRIC Study Principal Investigator, University of Manchester.

Over the past 2 years Pam and Yvonne from your support group have been part of the METRIC Study. METRIC is the study acronym for the ME Education, Training and Resources In Primary Care Study which was funded under the NIHR Research for Patient Benefit scheme which began in March 2011.

Pam is our service user/patient co-applicant on the grant. She helped to write the grant and Yvonne joined us after funding was agreed and to provide our carer input. They both attend team management meetings at the University of Manchester every 2 months and help us keep the research patient focussed and offer advice based on their own experience on how we can best carry out this study and encourage GPs to engage in this work.

We are pleased to report the publication of our paper which describes how we developed the resources used in the METRIC study: This is an open access journal so you can read the whole paper by going to the link: <http://www.biomedcentral.com/content/pdf/1471-2296-13-93.pdf>

Developing resources to support the diagnosis and management of Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME) in primary care. A qualitative study

Kerin Hannon, Sarah Peters, Louise Fisher, Lisa Riste, Alison Wearden, Karina Lovell, Pam Turner, Yvonne Leech & Carolyn Chew-Graham.

BMC Family Practice 2012, **13**:93 doi:10.1186/1471-2296-13-93

Background

NICE clinical guidelines (CG 53) emphasise the need for a confident, early diagnosis of Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME) in Primary Care with management tailored to the needs of the patient. Our research suggests that General Practitioners are reluctant to make the diagnosis (they don't feel confident making the diagnosis and often feel it isn't that helpful to their patients – which contrasts with patients who find it important to have a label to account for their symptoms and that this often represents the first steps in being able to try to access treatment). Not making the diagnosis means that many people can't be managed properly and GPs report that resources for CFS/ME management are currently inadequate. The METRIC study aims to develop resources for both patients & carers (METRIC Patient resource pack) and also healthcare practitioners - GPs and practice nurses - to support the diagnosis and management of CFS/ME in primary care.

Methods

We conducted interviews with 16 patients, 10 carers, 9 GPs, 5 practice nurses and 4 CFS/ME specialists in North West England during 2011-12. We looked at the existing literature on CFS/ME to decide what questions we should ask and developed interview outlines. Patient and carer interviews focussed on what experiences people had of being diagnosed and of what support they had received in primary care and what they felt would benefit them.

An Update from the METRIC Team: Cont ...

Interviews with healthcare professionals focussed on what training they had received and where they thought gaps in their training existed. The interviews were audio recorded, transcribed and we then looked at their content and what information was being given to us by grouping them according to themes.

Two patient involvement groups (one each in Preston and Bolton) were set up and met every 3 months. These groups had up to 6-8 members each (this allowed for relapses, other illnesses and commitments). The groups were consulted on the content, layout and additional material that they felt would be useful in the patient resources for people living with CFS/ME.

Results

Patients and carers stressed the importance of recognising CFS/ME as a legitimate condition, and the need to be believed by health care professionals. GPs and practice nurses felt that they do not have the knowledge or skills to diagnose and manage the condition. They expressed a preference for an online training package (it is often difficult to get all the staff of a practice available at the same time and place to deliver training).

We developed our training package for practitioners in two modules 1) diagnosis and 2) management, and this online training module is hosted by The Royal College of General Practitioners on-line learning, which means that after METRIC study ends the module will still exist and can be used long term.

For patients, information on getting the most out of a consultation and the role of carers was thought to be important and this was added into the patient resources. Patients did not want to be overloaded with information at diagnosis, and suggested information should be given in steps. We therefore developed a menu system so patients could choose what information they wanted from their GP and the pace that they were given these. The topic sheets were mainly based on specific symptoms; fatigue; memory & concentration; pain; sleep; stress, anxiety & depression; and also sheets on diet & nutrition; information for carers; newly diagnosed CFS/ME; tips from others with CFS/ME; work & education. We also made a DVD, to help information sharing with carers and family, and also for those whose symptoms act as a barrier to reading. This DVD features experts in the field of CFS/ME, GPs, CFS/ME specialists, patients (mild, moderate and severe) and their carers, and Pam has a starring role where she shares information on her own CFS/ME.

Conclusion

Traditionally in medicine, experts decide what information should be given to patients. This study turns this process on its head and uses a patient and carer-centred method to develop the patients and carer information (the DVD and symptom based leaflets) and training for health care practitioners. We believe this will help ensure that the resources are acceptable to patients and their carers. The healthcare practitioner training modules should equip GPs to diagnose and manage CFS/ME effectively, allowing the NICE guidelines to be met and giving patients acceptable, evidence-based information.

We are currently evaluating these resources in GP practices in Manchester, Stockport, Salford, Bury, Bolton, Trafford & Central Lancashire as part of the next phase of the study. We look forward to reporting this and updating you once this is complete.

The Wedding of 2012



On November 3rd 2012, Susan Forshaw (who is our greeter at the door for our Longsight Social) married John Critchley at the Red Hall Hotel. They had a really magical day surrounded by their family and friends and our own Pam Turner was a witness along with Paul Critchley, John's brother. So a big hearty congratulations, to Susan and John and wishing you both a long and happy life together.

(Top left photo: from left to right: Pam, Susan, John and Paul. Top right photo: the happy couple Susan and John Critchley).

Nom De Plume March. Stuffed Dates

Common to those with our condition, I have a plethora of allergies and intolerances to navigate myself through. Though this initially served to irritate and concern me, I soon began to exploit the situation so I might challenge and strengthen my culinary interests. As time has passed, I have lost any urge to cheat myself into temptation as the gains are too fleeting, and the costs too high.

My husband and I do our best to remain responsible shoppers and eaters, and our primary concerns are how food is farmed, processed and sold. The food industry however is very canny, which means that in order to sustain our principles and maintain our health, it is vital to continually check all processing methods and ingredient listings.

For the fortunate, high days and holidays represent the gathering up of loved ones, with whom we share a feast with. Indeed, certain events are inextricably linked to dishes one might ordinarily dismiss, such as pancakes on Shrove Tuesday, chocolate eggs on Easter Monday and brandy butter intended to serve with Christmas pudding. Of course these traditions can range vastly from culture to culture and family to family.

So as we move closer to Easter, marzipan creeps back into view. In contrast to our European cousins, who eat it much more than we; here it is an ingredient used chiefly to top and decorate Simnel cakes. Frangipani, which to my mind is a more authentic, rustic version of Marzipan, is an absolute joy to make. Its warm mellow aroma, when coupled with its chunky texture, is a much welcomed treat during these cold hesitant days towards spring. I also admire its practical attributes, as it can be made well in advance, frozen, and used in endless ways to transform a rudimentary dish into something exceptional.

However a great deal of recipes pertinent to this ingredient rely on the inclusion of wheat and dairy, which like many other M.E sufferers I have to avoid. Consequently I have spent years testing out alternatives, so I may be spared disappointment while avoiding allergens.

I spend a lot of time in my kitchen and pantry. Kilner jars which form the heart of my pantry. These stand tall and full like a myriad of building blocks I can use to compose from.

I am mindful that the description of Frangipani I have shared conveys a food which is layered with various tastes and aromas. But Marzipan is sweeter, denser and all together smoother proposition to its culinary forefather.

Just as my Grandma's influence continues to inform all I do, the same must be said of my Mum. When she is not aware of me looking, I sometimes witness her legs as they swing back and forth as if her kitchen chair has become animated. It is a sight made more touching by the happy expression her brief abandon promotes, as she continues to chomp away looking deep into space.

Sometimes the simple pairing of different flavours or textures is all that one cares for. And so here, dear reader I offer you a dish with such a sentiment in mind, whilst also wishing you a happy Easter and jubilant Mothering Sunday.

Though this recipe calls for few ingredients, resist any temptation to compromise on quality. For instance, with regards to the dates, please dismiss purchasing old, cheap, and cloyingly sweet ones, instead and if at all possible, visit an Indian or Middle Eastern grocer to source a plumper, fresher quality of fruit, traditionally eaten during the Ramadan period of the Islamic calendar, as well as something commonly served to complement a shot of bitter black coffee. What you are looking for, is fruit that has a deep purple brown tone with a skin so soft, that biting into it is a comparable to one settling into a cherished Eiderdown.

Ingredients you will need:

- quarter of a packet of Organic Marzipan
- 12 dates
- the zest of an organic Orange
- a handful of flaked almonds.

Method:

1. Begin by toasted the almonds until each side has turned a rich golden brown.
2. Removed from the grill and allow them to completely cool.
3. Slowly, lovingly pit each date by drawing a straight line through one side of your fruit with a sharp knife. Remove the long stone, by teasing it away from the date's skin in a fashion similar to when one is gutting a fish.
4. Discard the stones. Zest the peel from the orange, which one now kneads into the mound of Marzipan. When evenly combined, generously stuff each pitted date with the orange infused marzipan. Each fruit should now have its own full belly that requires garnishing with the almonds. Do this by inserting as many flakes as each date can accommodate.

Wrapped in Greaseproof paper and tied with string, these dressed dates will last the duration of Easter, but gifting them to loved ones insures an altogether shorter existence.

Greater Manchester Neurological Association

We have received an advert from Greater Manchester Neurological Association for their next meeting, hosted by the Stroke Association, Rochdale. Monday 11th March 2013 10 am - 12noon. At Castleton Community Centre, Manchester Road, Rochdale OL11 3BS. Guest speaker Lesley Mort, Chief Officer Designate, NHS Heywood Middleton and Rochdale Clinical Commissioning Group. Entrance is £2 which includes Tea, Coffee, Biscuits and a free draw.

If you want to get the info from GMNA direct to you please let them know. e-mailinfo@gmneuro.org.uk

Urgent Research Request!

As you already know from last months newsletter Dr Raymond Perrin urgently needs volunteers for some new research at his practice in Prestwich!

He is conducting a Practice Day to determine if ME can be diagnosed purely by his osteopathic methods, he already has enough volunteers with ME, but still needs volunteers (who are not a blood relative, also aged 18-60, and does not have ME. It can be anyone else, such as a non-blood relative, neighbour, friend, etc). Neither of you must be known to Gail Sumner or himself. If you are able to participate in this exciting new research, please phone their clinic on 0161 773 0123 telling them you wish to participate in the Practice Day and you found out about it from the Bury/Bolton ME Support Group.

Summary:

Who? Someone who is 18-60, not a blood relative and does not have ME. Neither should be known to Dr Perrin or Gail Sumner.

Where? Dr Perrin's practice in Prestwich.

Why? To see if ME can be diagnosed using Dr Perrin's osteopathic methods.

When? On a Sunday (date to be confirmed) and it will take about an hour.

How do I sign up? Call the practice on 0161 773 0123 and tell them you want to participate in the practice day and that our group sent you. Thank you!

ESA Appeals Nightmare Confirmed

Latest news from Benefits and Works on Tuesday, 26 February 2013.

Claimants could be left without any income replacement benefit at all when challenging a decision that they are fit for work, the government has confirmed. Once the new system of mandatory reconsiderations before appeals is introduced, employment and support allowance (ESA) claimants will lose their right to be paid the assessment rate when they first challenge a decision.

Instead, they will have to try to sign on as available for work and claim Jobseeker's Allowance (JSA) or manage without either benefit until the reconsideration has been carried out. Only once an appeal has been lodged will they be able to reclaim ESA. The decision to refuse to pay ESA during the reconsideration period was confirmed by Lord Freud on 13 February, when he told the House of Lords:

"I turn now to ESA. At the moment, if someone appeals a refusal of ESA, it can continue to be paid pending the appeal being heard; this is not changing. What is changing is that there can be no appeal until there has been a mandatory reconsideration. So there will be a gap in payment. In that period-and I repeat that applications will be dealt with quickly so that this is kept to a minimum-the claimant could claim jobseeker's allowance or universal credit. Alternative sources of funds are available. Of course, he or she may choose to wait for the outcome of the application and then, if necessary, appeal and be paid ESA at that point."

However, there is no time-limit for how long the DWP can spend carrying out a mandatory reconsideration. Given the ever increasing workload and ever decreasing staff numbers, the probability of reconsiderations being carried out in weeks rather than months does not seem high.

In addition, some people attempting to claim JSA may find Jobcentre Plus staff attempting to refuse to accept their claim on the grounds that, because of their health condition, they are not available for and actively seeking work. This may be particularly the case as claimants are likely to be required to continue submitting sick notes in relation to their ESA claim whilst presenting themselves as fit for work in relation to their JSA claim. Claimants may well find themselves in the nightmare scenario of being found too fit to claim ESA but too sick to claim JSA.

Even the start date for the new mandatory reconsiderations for ESA is the subject of confusion. DWP and ministerial statements refer to a start date in April for PIP mandatory reconsiderations and October for ESA. The draft regulations, on the other hand, give a start date of 8th April for PIP and 29 April for ESA, JSA and universal credit mandatory reconsiderations.

Late Edition

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

It's possible to recover from CFS/ME, if an individual is willing to participate in therapy addressing mental and physical well-being. Researchers from Queen Mary, University of London, have found that Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET), as supplements to specialist medical care, increase the likelihood of recovery from CFS three-fold compared to other treatments studied. Recovery from Chronic Fatigue Syndrome Possible - Prohealth - Feb 10 2013

Meanwhile on the House of Lords, The Countess of Mar, started a debate on the PACE trial, which advocates the use of CBT and GET to help CFS/ME patients. She pointed out that despite evidence from the Medical Research Council that biological factors were source of CFS/ME, the view put forward by the PACE trial still held sway. At the end of the debate, the Government expressed sympathy with patients, and said they were committed to "investing in improved services for CFS/ME patients and in an expanded research programme." House of Lords debates the PACE Trial - ME Association - Feb 7, 2013

Researchers say fatigue may be an important symptom of adult attention deficit/hyperactivity disorder ADHD, and that people with ME/CFS or other types of persistent fatigue should be looked at for ADHD. Their new study looked at three cases of ME/CFS in people who'd responded poorly to treatment. Researchers found that all three met the criteria for ADHD, and all three responded well to psychostimulant medications, which are a common part of ADHD treatment. Chronic Fatigue Syndrome & ADHD: What's the Link? - About.com - Feb 13 2013

The CFS Research Foundation, is funding a new 3 year study into why so many CFS/ME sufferers experience heightened pain. The research team will be composed of scientists and clinicians at Bart's and the London Medical School, Imperial College and Imanova, a centre of excellence for imaging sciences. UK Charity Launches Major Study Into CFS/ME and Pain - Prohealth - Mar 3 2013

A new journal called Fatigue: Biomedicine, Health & Behaviour will soon be published due to the high numbers of articles being published about fatigue. Sponsored by the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME) and supported by a distinguished multidisciplinary editorial board of international scientists and clinicians, Fatigue is the first biomedical and behavioural journal focused on fatigue. New journal aims to address fatigue in medical illnesses and specific ... - News-Medical.net - Feb 26, 2013

In the USA, Somatic Symptom Disorder is a new psychiatric disorder which some groups fear will make it easier for doctors to dismiss patients as mentally ill when in fact they have a physical illness. New Psych Disorder Could Mislable Sick as Mentally Ill - ABC News - Feb 27 2013

NEWS FLASH!!! Bedroom Tax!!!

Those of you, who are going to be affected by the bedroom tax, have probably received letters saying how much you'll have to pay from April 1st. But how many of you have also received a letter from your local Council telling you to apply for **DHP (discretionary housing payment)**, you can apply for this and get the amount paid for you. This information was in the Times on Tuesday 26th February, and also been mentioned on lots of other websites. We hope this helps those of you that will be affected and urge you to share this information with other people who don't know about it. Below you will find the direct web links for Bury and Bolton's discretionary housing payment information page.

Bury Council Web site Discretionary Payment page: <http://www.bury.gov.uk/index.aspx?articleid=3969>

Bolton Council Web site Discretionary Payment page:
<http://www.bolton.gov.uk/website/pages/Discretionaryhousingpayments.aspx>