



Welcome to Our January 2016 Newsletter.

Note from the Editor Maxine: Remember the Prestwich social has changed venue to **The Woodthorpe, Bury Old Road, Prestwich, M25 0EG.**



Monthly focus.

AGM advanced warning date 17th March 2016, Caroline is collecting raffle prizes.

What types of guest speakers would you like to see at the main meetings? If you know someone that would be willing to speak please email maria113@talktalk.net

Volunteers: We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) you think you can contribute, or are up for a certain task, please contact Caroline. **We are really struggling to keep the group going**; we are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 01204 525 955 for more information.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). The building is past Morrisons/Home Bargains/Brightmet Health Centre on the right hand side as you go into town, very near the junction before you turn onto Crompton Way from Bury Rd.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday January 21st 7:30pm. Social Evening. We'll probably still be recovering from Christmas and can ease ourselves into the year with a social!

Thursday February 18th 7:30pm. Maria talking about Devo Manc. Our very own meetings secretary will be talking to us about the DevoManc proposals, as she has been to many, (many, many) meetings on our behalf about it. These are plans to devolve responsibility for health and social care to statutory organisations in Greater Manchester.

Thursday March 17th 7:30pm. Our Annual General Meeting and raffle. Please consider us for any unwanted or duplicate gifts that we can use as raffle prizes.

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. Please contact our instructor Lisa. Mobile: 0770 803 66 36 Email: lisayogatori1@gmail.com. **Our yoga classes are currently being funded by The Big Lottery Fund.**

Prestwich Socials: *****PLEASE NOTE CHANGE OF VENUE. *****Due to parking problems at The Church Inn, **from January** our Prestwich social will move to **The Woodthorpe, Bury Old Road, Prestwich, M25 0EG**. This is a very roomy pub, with ramp access, a disabled toilet, a variety of comfortable seating and free parking outside. It also serves a range of full meals and snacks if anyone is hungry. We meet on the **second Wednesday** of the month at 2pm, so the next meeting is **Wednesday 13th January 2016**. **Wednesday 10th February 2016**.

Please try not to turn up too late, because if numbers are low and those attending are not feeling very well on the day, it would be a shame if you missed us.

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.



DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Trustees, nor the Bury & Bolton ME/CFS & Fibromyalgia Support Group (Registered Charity Number: 1161356). Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Reminders:

Equipment to Borrow: We have a wheelchair, and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846. To trial the SmartCRUTCH's, call Caroline on 01204 525 955.

Social Media: Please follow us on twitter on: @BBMECFS

Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecfs/

And our new open page

<https://www.facebook.com/bbmecfsopen>

Don't forget our own web page <http://www.mesupportgroup.co.uk/>

Recommended GP's: Don't forget, we have a list of recommended GP's! If you have a sympathetic or helpful GP, please let us know, as people ask us for one in their area all the time. 01204 525 955, caroline@mesupportgroup.co.uk.

Newsletter Articles: Please carry on sending us anything you would like to share with the rest of the group; whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Deadline for the newsletter is the last day of the month. Please send your contributions to: maxine@mesupportgroup.co.uk. Via email where possible please.

Amazon: 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.

Appeal to go paperless:

A large portion of outgoings is photocopying costs – awareness leaflets, welcome packs, monthly newsletters and several lengthy BenefitsAndWork.co.uk guides. It would help cut printing and postage costs (as well as our volunteer's energy, electricity and time) if you would get the email versions of the benefit guides and newsletters if you are able to please. (If you do not have access to email/a printer, does a friend or relative?) Could you also return the guides where possible so we can pass them onto other members to re-use, and also save some trees). Only around 40% of our newsletters go out by email. Of course we know not everyone has email, but if you can get the newsletter this way, please would you consider it to save us funds. A huge, unseen amount of work by people with ME/CFS/FM goes into them, producing these and getting them to you. Please contact caroline@mesupportgroup.co.uk / 01204 525 955 to switch to email newsletters. Thank you.

Benefit and Work Guides, Please don't forget that we have benefit information guides that we may distribute to members via a purchased group publishing license. Please do not photocopy them, upload to the internet, or redistribute to non-members. Due to the cost in photocopying, it would be appreciated if they could be returned after use. The email versions save us pennies and volunteer energy.

If you would like one, please call Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk

DLA, PIP & AA. No one aged 16 or over can make a new claim for DLA, you must now apply for PIP. Only people claiming for a child under 16 can make a new claim DLA.

Personal Independence Payment:

Claiming Personal Independence Payments (PIP) (70)

Example PIP Diary Extracts for CFS (3), FM (2), arthritis (3), mobility (3), anxiety & depression (2), blank template (2)

PIP Appeal Submissions (33)

Ways to Challenge a PIP Medical Report: Over 50 Grounds of Appeal With Sample Texts (24)

I've Been Awarded PIP, What Else Can I Claim? (12)

Attendance Allowance: Attendance Allowance Claims On Physical & Mental Health Grounds (44)

The best possible support for clients with DLA and AA appeals (44)

Disability Living Allowance: DLA for adults physical/mental grounds (60)

DLA claims for children on mental/physical grounds (67)

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

The best possible support for clients with DLA and AA appeals (44)

Appealing against a DLA decision (19)

DLA adult renewal claims on physical (58) and/or mental health grounds (50) Changes of circumstances for people claiming DLA (8)

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

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

Employment Support Allowance:

Being transferred from Incapacity Benefit to ESA (22)

ESA claims for mental health difficulties (86)

ESA claims on physical grounds (84)

ESA Appeal Submissions (26)

ESA Mandatory Reconsiderations and Appeals (40)

Permitted Work (6)

Pathways to Work Interviews (10)

Other:

Which benefits can I claim? (9)

Getting help with your benefits (12)

Getting better treatment from the DWP (12)

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

Caution, may not count as voluntary work (6)

Am I covered by the Disability Discrimination Act? (9)

Reasonable adjustments: Employers and Jobseekers (9)

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

Bedroom Tax Case-Law Round-Up (7)

Caroline's Visit to the Senior Moggies



I know a lot of our members are big fans of the four legged furry pet variety, so here's some pictures of my visit to Bleakholt Animal Sanctuary.

For my 30th birthday (New Years Day) I wanted to do something nice and meaningful, yet within my limited energy levels. I quickly set my heart on cuddling elderly cats in a shelter/sanctuary, who might otherwise not get much one on one attention, especially around that time of year. A room packed with cats is my idea of a great time, not so much my

husband's (or most other people). However, being NY Day, virtually nowhere is open, including most animal shelters.

Bleakholt Sanctuary in Edenfield was open for a couple of hours in the morning though, which required getting up early. It felt a bit like going to the airport on holiday because I usually don't see that time of day.

Our family is no stranger to Bleakholt having adopted various animals from there over the years. Bleakholt has cats, dogs, rabbits, guineapigs, sheep, pigs, horses, chickens, etc. The younger adult cats have large outside pens with heated shelter and the oldies are in a warm building, roaming free (so shut the door quick). The sick cats are in bays in a separate area.

The seniors room has an area downstairs where they descend on you for food and attention, and try their best to escape (Minnie, aka Houdini, that's you). The cats just appear from places, there's quite a few hidey-holes going up the walls as well as beds hidden in large tubes. Upstairs there's two rooms, but most favour downstairs from what I've seen. I think because they can see the staff making their dinner.

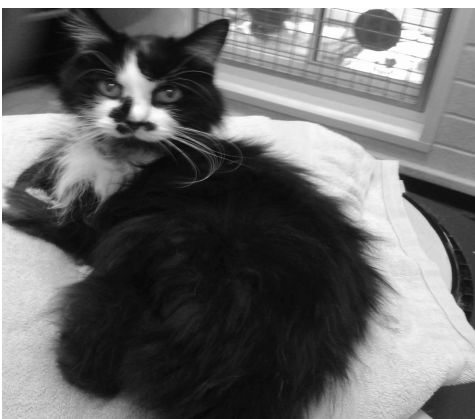
You can tell who the boss cats are, but they were all very confident and came to say hello, immediately competing for our laps.

One or two would voice their displeasure at not having any strokes or cuddles, so you kind of wish you had eight arms and six legs to accommodate them all.

I brought some cat-nip toys with me to give them a bit of fun, and they went completely mad on the stuff. You had to supervise them with it as they got rather possessive of their catnip carrots and candy canes, so a bit of a tiff would ensue if you didn't referee. They were rolling around on the floor and bunny-kicking the toys, you wouldn't know they were elderly cats. When we eventually and reluctantly left, we didn't have a problem as they were so chilled that they didn't try to get out (or they didn't notice us going).

One cat gave us lots of giggles, as he was furiously trying to stuff himself into my coat pocket. I told Steve that he must have been desperate to be smuggled out and come home with us (he didn't believe me sadly, I'm not allowed anymore cats). Since I'd stored the catnip toys in my pocket, it must have stunk of the stuff, and he was happily getting cat-high off my pocket fumes. The white long hair in the above picture spent over 20 minutes vegging out on the cat nip before I had to take it away because he wouldn't share.

My coat was covered in slobber and cat hair, and the cats were happy, each having a cuddle and a go at the catnip. There was a lovely ginger and white boy, with a weathered face who really got to me, and was relieved to hear he was going to his new home the day after, at the age of 18. There were a few long haired cats in, who had arrived in terrible condition, fur terribly matted, requiring anaesthesia to shave them (like Robyn here, her neck fur has still not grown back for some reason).



I'm going to go often hopefully. There's a shop on site, proceeds support their work, so I spent a lot of time in there as well! They also have a café at weekends, and open days throughout the year. You can adopt many animals there, and they also can microchip your pets.

Animal sponsorship gifts are available, like that of Duke, a horse who looked so very very tired when we looked round the stables last year. We found out he

had degenerative joint disease, so he was much like myself! Duke is an 8 year old Irish Draught X Connemara gelding. The Degenerative Joint Disease means that he can no longer be ridden and has had to retire at a very early age. He is on medication to make him comfortable, and is walked around as much as possible to keep his joints moving.

You can volunteer for the Sanctuary in various ways like cuddling the cats or helping in their charity shop in Ramsbottom, or walking the dogs. Their website lists some animals available to adopt, but a visit in person is best for up to date information and to see them face to face.

Bleakhol Animal Shelter costs £1 million to run each year, not counting developing their facilities. Bleakholt Animal Sanctuary, Bury Old Road, Edenfield Ramsbottom, Lancashire, BL0 0RX Telephone: 01706 822577 <http://www.bleakholt.org>. Reg Charity #1110503

Understanding Cellular Energy Production by Sarah Wragg:

Article first published in the Nutrition I-Mag www.nutritionimag.com and reprinted with kind permission.

Ongoing fatigue can severely affect the quality of life for many individuals. Sarah Wragg explores the underlying metabolic defects associated with energy production:

Fatigue can come about as a side effect of a high-octane lifestyle and is also a common symptom associated with many 21st century health conditions such as multiple sclerosis (MS), Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Fibromyalgia, bowel conditions, adrenal insufficiency and Type 2 diabetes, not to mention various types of infections and cancer.

Sales of energy drinks loaded with sugar and caffeine are exploding in popularity as an increasing number of people turn to short-term solutions to help boost their vitality. Fortunately, nutritional therapy can offer a healthier, long-term approach to improve energy levels and overall health.

Energy:

The body needs a constant supply of energy to build new molecules, enable movement and transport substances whilst creating new cells. A whole series of metabolic reactions are required to 'capture' the energy from our food and trap it in a form that the body can use. Cellular structures called mitochondria are the most important source of cellular energy and it's estimated that mitochondria make up 10% of body weight, approximately 10 million billion per adult.

Understanding how mitochondria generate cellular energy can also help us determine what can go wrong, which is crucial for supporting clients with any form of chronic tiredness. The mitochondria generate energy by a process of oxidative phosphorylation involving molecules of ATP (adenosine triphosphate), which is hydrolysed to ADP (adenosine diphosphate), releasing energy. ADP is quickly phosphorylated back into ATP and so the cycle continues. This cycle continues approximately every 10 seconds in a normal healthy body and is capable of producing more than 90% of cellular energy.

However, if the mitochondria are not efficient at recycling ATP, then the cell quickly runs out of energy, causing symptoms of poor stamina. The cell literally has to hibernate, waiting until more ATP has been manufactured. If the cell is pushed (i.e. stressed) when there is no ATP, then it will start to use ADP instead, converting the ADP to AMP (adenosine monophosphate). The problem here is that AMP is lost in the urine which

means that ADP is unable to be recycled and must therefore be rebuilt from raw ingredients such as D-ribose, a process which takes days, resulting in 'delayed' fatigue.)

Dysfunction:

There is considerable evidence that mitochondrial dysfunction is present in individuals suffering from CFS. In essence, the pathology involved with CFS is that of slow recycling of ATP to ADP and back to ATP again. However, there is another problem. During times when the cells are extremely short of ATP very small amounts of ATP can be made from glucose via conversion into lactic acid. This is very common with CFS sufferers and leads them to switch into anaerobic metabolism. However the resulting lactic acid build-up which particularly occurs in the muscles causes a sensation of heaviness and aching. When mitochondria function well, lactic acid is quickly converted back to glucose through ATP and the lactic burn disappears. But if there is no ATP available – for example, during times of mitochondrial dysfunction, then the lactic acid persists, causing great pain and tiredness. Dr Myhill has demonstrated the power of the ATP Profile Test in confirming and pinpointing biochemical dysfunctions in people with CFS.

Insulin link:

Mitochondrial dysfunction has also been linked to insulin resistance (IR). According to research, individuals with IR have unusual fatty acid-stimulated changes in mitochondrial uncoupling proteins (UCPs). This results in an increased production of reactive oxygen species (ROS) and ultimately fatigue. But why does this happen? When mitochondrial respiration functions properly, the amount of ROS produced as a consequence of electron transport activity is effectively neutralised by antioxidants. Individuals with IR have been found to have approximately half the normal levels of UCP3 in their skeletal muscles. UCP3 prevents the build-up of excessive concentrations of ROS and removes fatty acids (formed by oxidative reactions) that can build up in the mitochondria. Fatty acids are particularly sensitive to ROS oxidation and result in damage to mitochondrial components if not controlled. The link between IR and serious fatigue may indicate that mitochondria dysfunction is also present.

Damage:

Damage to cellular mitochondria can impair the ability of cells to produce high-energy molecules, such as ATP. ROS damage generally accumulates because antioxidants cannot restore or replace ROS-damaged molecules fast enough. This can happen through ageing or because of an excess ROS production by the mitochondria, or lack of antioxidants. At the molecular level, damage to DNA, phospholipids and other lipids within the mitochondrial membranes caused by ROS can affect mitochondrial functioning and energy production. Ultimately fatigue follows.

There are ways to prevent this damage and reduce energy loss, however. Reducing cellular and mitochondrial membrane and DNA damage plus loss of membrane integrity are a starting point. This can be achieved, in part, by neutralising ROS with various antioxidants. However, antioxidants alone may not be the answer as they may not completely eliminate or reverse ROS damage. Some fascinating research conducted by Prof Nicolson and Dr Rita Ellithorpe provides further information. Glycophospholipids help replace damaged mitochondrial membrane phospholipids and other lipids. Glycophospholipids can therefore provide direct impact on production and maintenance of energy in fatigued clients. The clinical application of what is being commercially known as 'Lipid Replacement Therapy' which contain glycophospholipids amongst other lipids, antioxidants, nutrients, probiotics, vitamins, minerals and plant extracts can help strengthen the battle against fatigue.

Nutrients:

Minerals such as iron, copper, zinc and vitamins such as biotin, B6, B12 and B5 support mitochondrial function. If dietary intake of these vitamins and minerals is inadequate, electrons derived from food cannot move efficiently through the energy-producing steps. Instead of contributing to energy production, the electrons help increase production of ROS, increasing the rate of mutations in mitochondrial genes. It is at this point, the crossroads between mitochondrial energy production and ROS production, that diet could influence energy levels.

Re-charge:

1. Have rest days. These allow the mitochondria to recover, this is extremely important if the individual has a high exercise regime.

2. Acetyl-L-Carnitine – acts as a cargo train, transporting the fatty acids into the mitochondria whilst removing any metabolic rubbish (through its antioxidant support in controlling ROS damage). Protein foods provide a rich source of acetyl-L-carnitine.

3. Sports – Consider acetyl-L-carnitine and creatine for athletes or those committed to extreme exercise. The muscles typically have five seconds of ATP in their stores. This means that ATP reserves can be exhausted and depleted very quickly. Supplementing creatine helps to provide an immediate ATP loan, like an ATP overdraft facility, to exercising muscles.

4. Feed the mitochondria – ensure the diet supplies a good supply of the vitamins and minerals associated with mitochondrial needs.

5. Antioxidants – these help to mop up ROS. Include vitamins C, E, zinc, coenzyme Q10, N-acetyl cysteine, alpha-lipoic acid. CoQ10 is an important co-factor for the synthesis of ATP.

6. Glycophospholipids – these membrane lipids are obtained through foods such as meat, egg yolks, fish, turkey, chicken and beef.

7. Support – other nutrients to consider include D-ribose, NAD, magnesium and B12 plus essential fatty acids to further support the mitochondria. These help to restore normal function and support level.

Mitochondria are the most important source of cellular energy and if their function is impaired, available energy is limited. Restoration of mitochondrial membrane integrity and fluidity are essential for optimal functioning. Ultimately we need to address the underlying causes as to why there is mitochondrial damage and put in place a strategy to prevent ongoing damage. Factors that need to be considered include diet and nutrient deficiencies, toxic load, digestion, blood sugar and insulin balance, thyroid function, adrenal activity, presence of allergies and over exercising. Nor should emotional state and stress be forgotten. Together these factors could play a major role in the ageing process and prevent degenerative diseases – not just simply helping to give us energy.

Sarah Wragg gained a BSc (Hon) degree in Nutritional Therapy from the Centre for Nutrition Education & Lifestyle Management (CNELM). She is a certified NLP practitioner with particular interests in digestive complaints, fatigue, weight and children's health. Sarah has clinics in the Richmond/Wimbledon area. info@mattersforhealth.co.uk 07702 492302