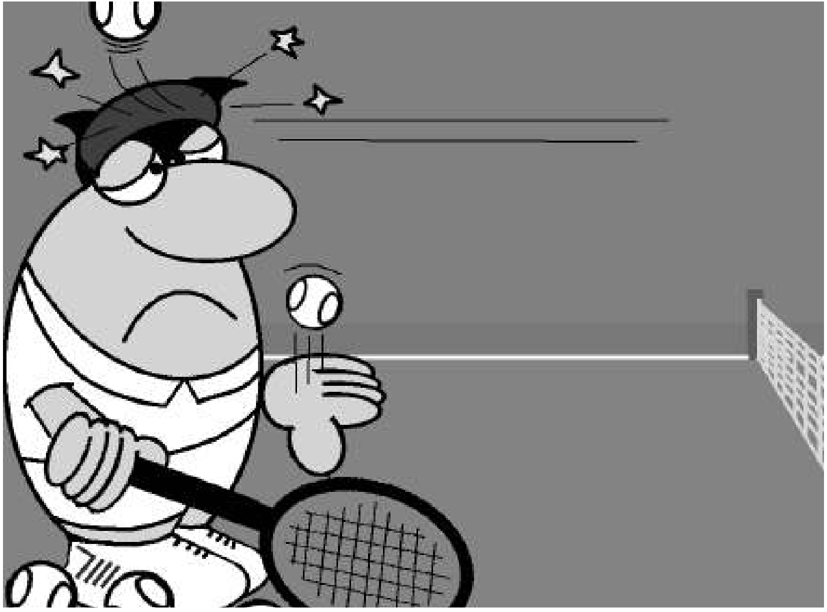
BBME

Support Group

"Breaking the Isolation"

Welcome to Our July 2014 Newsletter

Note from the Editor Maxine: Welcome to this months newsletter. Don't forget, no meeting at Longsight, Harwood in August. Caroline has made an event on the Facebook page for people coming to the July meeting to post what food they are bringing so we don't get too many duplicates. If you are not on the Facebook page then please feel free to phone up and enquire.



After the onset of CFS Charley experienced some fundamental changes in his sports life.

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.

Contents of July's Newsletter.

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.

Issue: 97 **July 2014**

Dates For Your Diary

Longsight, Harwood Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church (the big stone building with an elongated wheelchair ramp outside, not the smaller church hall opposite), Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). There is a car park and blue badge parking on the street and the building is wheelchair accessible. Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday 17th July 7:30pm Bring and Share Supper Summer Social: Our second annual bring and share summer supper, where we all bring food to share. There are always plenty of leftovers and lots of gluten/egg/dairy free, etc.

NO MEETING IN AUGUST

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. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

Radcliffe Socials: From June, our Radcliffe social will move from the Sparking Clog, to the **Bradley Fold Garden Centre.** They are on the first Wednesday of the month at 2pm. They next ones will be **Wednesday 6th August** at 2pm. There is disabled parking and is wheelchair accessible. If you use the entrance, you will have to walk around the garden centre to get to the café. It is a much shorter walk if you use the “exit” doors and take an immediate left to get to the café. The café serves hot and cold drinks and food and snacks. We will put our newsletter on the table, so you can recognise us. The address is Moor Road, Radcliffe, Bury BL2 6RE

Prestwich Socials: Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ.** This has level access and free parking outside. This has got the thumbs up! The staff were friendly and helpful and we could hear each other a lot better.

August’s meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 13th August at 2pm. Please check on Facebook first to check it is still going ahead, as that’s the quickest and easiest way, or call Maria on 07867 862 341 if you are not on Facebook.** Apologies to those not online, but it is either this, or stop them altogether.

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.

FESTIVAL MEDICAL SERVICES FMS

COMIC RELIEF

Supported by Bolton Council

The BIG Bolton Fund...

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.

Social Media: Please follow us on twitter on: @BBMECFS
Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecfs/
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.

Radar keys: Currently sold out and no date to when new stocks can be sourced.

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.

Benefit and Work guides: Remember, for anyone filling in benefit forms or if you have appeals/tribunals, we have excellent guides available via post or email (saves us funds). Phone Ruth on 0161 766 4559 or email ruth@mesupportgroup.co.uk.

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.

Mercure Bolton Health Club Discount: The Bolton Mercure branch has kindly agreed that our members can use the swimming pool and sauna for only £3.50 per visit, and accompanying carers will pay the same (no charge if they don't use the facilities). The usual price is £8. Just say that you are a member of our group! The best times to use the club are before 4pm weekdays, Saturdays 1-5pm, and all day Sunday (but is busier if it is raining). Their address is: Mercure Bolton Georgian House Hotel, Manchester Road, Blackrod, BL6 5RU. Tel: 0844 8159029. If you would like help in approaching your local club for a possible discount for the group, please get in touch!

Hydrotherapy sessions: Preston and Chorley Fibromyalgia and Chronic Pain Support Group have kindly offered to let our group attend their private hire hydrotherapy sessions. **From June, there is now a Saturday session as well as the Friday one.**

The sessions are 12pm - 1pm on the first Friday of the month, and the third Saturday of the month at 1:15 - 2:15pm. They are at the Jubilee Pool, Tennyson St, Bolton, BL1 3HW. It is £3 per person and carers are free. The sessions will be on:

Saturday 19th July 1:15- 2:15
Friday 1st August 12-1pm
Saturday 16th August 1:15- 2:15

The pool is 34.9 degrees and air temp is 38.9 degrees so it is lovely and warm. They supply pool noodles, hoists and they have a stair case to get into the pool. I went in April for the first time and I thought everyone was really friendly and welcoming.
Please text or phone Natalie on 07855 777636 if you are planning to attend, so they know how many people might be going. Thank you to group leader Natalie for the generous offer to our members. If you have any questions or are interested and want more information, please contact Caroline on 01204 525 955.

Bury/Bolton ME/CFS Support Group Meeting June 2014 –Reiki

For our June meeting, Tracey Hughes from The Holistic Retreat in Tottington came to talk to us about Reiki.

Tracey set up business four years ago after working in advertising. Tracey became interested in mind body spirit connection and how positive energies make us feel good and negative energies make us feel bad. Through this, Tracey began to get interested in Reiki.

There are three levels of attunements in Reiki
level 1 - Self attunements
level 2 - Practise on other people
level 3 - Reiki master

Translation of Reiki:
In Japanese Rei means higher intelligence and Ki meaning universal life energy. It was developed by a Japanese man called Mikao Usui and brought to the western world in the 20th century.
Reiki is the use of the universal life energy to work holistically. It’s a natural healing by channelling energy through the healing practitioner to the recipient.
Reiki helps relieve stress, helps reduce pain, release emotional blockages and accelerate natural healing process and compliments traditional medicine in hospital, in treatment of cancer.

How It Works:
Ki- the energy is used without thinking on an everyday basis , for example using placement of your hand on your head if headache, toothache you place on your hand on your face, this subconsciously transfers energy. Ki - universal life energy maintains all living things, you can’t see it but we respond to it all the time, we can say 'ooh she has a wonderful aura' or 'you cut the atmosphere with a knife'. You can feel the energy when in a room or place.
When the energy is high we feel controlled when it’s low we begin to feel ill or blocked . Ki (energy) is received through sunshine and food or you can improve it through breathing or meditation. Energy flows through and around us is our auora.

We can store negativity all over our body, internalising our thoughts and feeling affects us physically, Chakras are the energy centre about an inch away from our body. Stress causes the chakras to begin to go out of balance and begin to block our inability to feel good.

Chakras and What They Mean:

There are seven Reiki chakras
1. Root chakra - means foundation, when you're weak you can feel tired, openly cautious, afraid of change, but when its balanced we can feel healthy and secure.
2. Sacral root - means emotions and sexuality, when it's good you feel fulfilled and great but when it's not you can feel anti-social, not emotionally involved people unresponsive.
3. Solar plexus - means power self-confidence & self-esteem, spontaneity. When out of balance it goes into a metal slump, you're not feeling creative and can suffer low self-esteem.
4. Heart - means love, connection and emotion. When balanced you have all those feelings, but if your self-esteem drops you can think "poor me".
5. Throat chakra - means communication, an express things, when can affect expression effect our wellbeing.
6. Third eye - means intuition, it corresponds to brain, nose, face, eyes and almost all the organs situated in the head. It helps us to see into seeing bigger picture, it's the gut feelings. When it's blocked that's when we ignore intuition.
7. Crown – means spirituality, fulfilment and when it's worked on it helps to gives us more wisdom.

Reiki clears negative energy that is stored in our bodies it knows where to go.
Reiki practitioners know where the energy blocks are, leaving clients to feel a sense of release.
Reiki practitioners usually set an intention, for example if you say you're going to have a bad day you normally have a bad day.

What Reiki Feels Like:

Reiki feels like recharging a battery, practitioners scan where energies are low. One person might feel complete relaxation, some may see colours, some hear voices, and some feel like there floating or heavy. Some can just go to sleep, then full of energy. All experiences are different. One thing everyone has in common is people leave feeling positive and balanced. It is also about the connection with the Reiki practitioner so it is worth trying different people.

Reiki and the NHS:

Although perceived as an alternative treatment, it's used alongside cancer patients. Wigan, Wrightington and Leigh NHS trust have used it and said it had a real beneficial effect. One cancer patient said she had a wonderful experience. It helps people whose energies are low and need relaxation. Reiki is good for adults, children and even animals and even plants!
Reiki is for everyone and anyone can learn, you can be attuned and treat yourself with Reiki.

Reiki principles:
Just for today do not worry
Just for today to not get angry
Honour your parents, teachers and elders
Earn your living honestly.
Show gratitude to every living thing

Summary
Reiki is complementary, hands on, non-intrusive, holistic system that works on all levels, mental, emotional and spiritual. It's an effective and gentle chakra healing and balancing aid, it's safe to use by anyone anywhere and it's a unique experience. Treatments can take around 50mins to a 1 hour and has been around in eastern medicine for thousands of years.
You can listen to the audio of the meeting (mp3 format) on our website:
http://www.mesupportgroup.co.uk/BBMEJuneHolisticTherapy.mp3
It is 28 minutes long. If you do not have internet access, please contact Caroline on 01204 525 955 for a CD copy. Many thanks to Tracey for coming to talk to us, and to Carol for typing up this article.

University of Bolton Patient and Carer Involvement Program

As mentioned in the last newsletter, there was an introductory event held in mid-June, to explain about Bolton University's Patient and Carer Involvement Program.
Maria and I attended, along with several other members of our group, to meet Tyler Warburton, Teaching Fellow at the University, who was very accommodating and had even provided gluten-free biscuits, decaff coffee and soya milk (he is well trained now!)

He explained about the University and their health care courses. Most people who access the courses are nurses, but other healthcare workers, such as physio's, occupational therapists also enrol. The new program they are working on is in partnership with Lancashire teaching hospitals, so will include many hospital sites and may be your local one. It is not just limited to Bolton.

For their upcoming Student Nurse course, they want patient and carer involvement from the outset, because there is very little at present.
They want to make sure that anyone enrolling on the course displays the values required (e.g courage, compassion and care) to be a Nurse, and we would like these people to be treating us in a few years time. Often, people may be qualified on paper, but when it comes to interview, it turns out them are unsuitable, or do not possess the people skills, or ability to think from the patients perspective.

They require patient and carers' input with:
Curriculum development
Patient mentoring of groups of 2 or 3 student nurses
Recruitment-sit in on interview panels or recruitment days with others.
Focus groups

Training and advice can be given for mentoring and recruitment days.
You can sign up for one or all of these activities. Everyone is welcome, you do not have to live in Bolton. If you are not well enough on the day-that's fine, it's not a binding contract and they know we have chronic illnesses! The only disease specific part of the course is the "Dementia Care" part of the syllabus. You may have had experience with this as a carer, as many of us discussed our own when we had the introduction event.

This is a great way of getting awareness of our illness and the impact it has on us, to future medical professionals. We often complain doctors and nurses don’t know about M.E, or don’t want to listen to us…here’s our chance! Please sign up as they are desperate for volunteers and input!!
<u>You will be reimbursed for your time. It can also be very rewarding to mentor someone and offer your input from your unique perspective.</u>

For more information about the program, please contact Tyler Warburton on 07871 552 690 or email Tw2ext@bolton.ac.uk . - Caroline

Tips for Living in Bed

Originally published on http://livingwithdisability.info/tips-living-bed
Reprinted with kind permission. **These tips may also be useful if you have a relapse, or are good to know if you are having surgery and have to spend a long time in bed recovering afterward.**

They say it must be nice to stay in bed all day. Really? Have they never wanted to do more? When you have no choice it's very different.
Twitter: @**latentexistence**

One of our loyal <u>Trabasaxons (a type of laptop bag with a soft base and hard tray surface, ideal for use in bed or wheelchairs)</u> has recently written a post giving fantastic hints and tips for people who have to spend a lot of time in bed. Danni wrote the post <u>Perfecting Bed Life</u> earlier this month and this post is inspired by her wonderful work with a few added tips.

Living with M.E. has meant Danni, in her own words, has ‘spent nearly every moment’ in bed for the past few months. Despite this she’s adapted and her post on how to make the best of managing your life from bed is extremely inspiring and we couldn’t help but highlight and share some of her top tips. Danni highlights a wide range of valuable products and ideas which can make living from bed a little easier.

Essential Gadgets for Long Term Stays in Bed

Getting used to an adapting to living from bed is difficult but here are a few tips that could be considered essential to your new routine and lifestyle.

Danni recommends investing in an over-bed table to make accessing things you need regularly easier. It’s also helpful for watching and using multimedia devices up close. An over-bed table falls short when sitting up becomes an issue and Danni suggests using your Trabasack in this case and a Trabasack is also an affordable alternative if you’re not sure about the space for an over-bed table in your home.

Danni also recommends another of our favourite products – the Hydrant, for drinking from bed as it stops the risk of any spills and they can be bought in large sizes. Replacement ends are needed when the device has been used regularly for a number of months. Hydrants are now used by the NHS to help ensure patients are kept hydrated in hospitals.

We also like the handsteady drinking cup that allows you tilt the cup right back using the rotating handle.ThehandSteady drinking aid stays upright, is easy to tilt and always keeps steady. Another simple yet essential tip from Danni is her suggestion that you should have as much stuff as you possibly can within reach. It's not always possible or appropriate to call someone to get stuff for you and maintains a degree of independence. This could mean having shelves installed near your bed or putting key items on the bed next to you where there's space. Bedside tables are ideal for storing snacks and medication.

Another alternative that we featured in a previous blog is a Telestik grabber or Handi reacher to extend your reach and access things that have dropped to the floor.

From a personal perspective it makes sense to keep the room as nice as you possibly can. Danni highlights that some people need rooms to be non-stimulating but others can benefit from nice pictures or being able to see out of the window.

Exercise and Pressure Sores in Bed: **Another essential key point is to remember to keep moving as much as you can. It is very easy to slip into the habit of staying still once you're living from bed but as Danni warns, bed sores are a genuine risk. If you can move yourself it's best to try to do so as much as you can, whether it's wriggling, rolling or whatever is best for your circumstances. If you're unable to do this then it's essential you have help to move position every two hours or so. Some people use sliding sheets or towels to help them roll and move in bed with the help of another person.**

Bed sores or to use their technical name pressure sores develop when a large amount of pressure is applied to an area of skin over a short period of time. They can become extremely painful and hard to manage and therefore keeping active from bed, in any way you can, really is essential. As Danni also mentions, a low cost idea is using a sheepskin can help with making the bed softer. If you do not move much and are spending long periods in bed it would be good to also ask your occupational therapist about a special mattress or even an inflating one.

Keeping in Touch: Our final essential point is to ensure you have an effective way of contacting your carers. This could be via a telephone, computer or if you live alone a panic button or cord. Wireless doorbells are another way of connecting with someone who may be in another room when you need support.

Comfort: Here we're once again taking inspiration for Danni and covering some of the ways to make your long-term stay in bed as comfortable as possible. Comfort is one of your top priorities and as Danni says 'most clothes are not comfortable for lying in' and there are clothes which are better. It's understandable you may not always want to wear pyjamas and t-shirts and leggings make a good combo. Danni also makes the great point of saying a cardigan or zip-up hoodie is a better option than a jumper as it's easier to take on and off.

Cushions and pillows are also great for comfort and u-shaped body pillows, often marketed as maternity products, can be a great option. They can be very supportive and can help you sit up if you find it difficult. The types of cushion and pillow which suit you will be very personal and you may want to try out different types.

Danni also highlights her trademark microwaveable penguins as great for keeping warm if you have difficulty moderating your body temperature. They can also ease chronic pain and aches of different kinds and if you don't fancy a penguin there are plenty of microwaveable body wraps and other animal characters too.

Oh, I forgot bras! This is probably more for those of us who are in and out of bed like me. Ordinary bras started to hurt like hell some years ago, especially when I was lying down. Lying down makes your diaphragm expand, which means that your bra suddenly feels like someone's wrapped a wire around your ribs and pulled. And that's before we get to underwires. My choice was no bra at all, which wasn't actually that comfortable and I hated how it looked if I had to get up and see people, or to faff around taking off my clothes, putting on a moderately uncomfortable bra, and then putting my top back on, every time I wanted to go out or have people over.

I did find a solution in the end. Look into maternity sleep bras, specifically the Bravado Body Silk. The whole thing is stretchy, it's comfortable lying down or standing up, and it actually gives pretty decent support. As well as daytime naps, I've occasionally slept in them at night when I've had bad breast pain.

Personal Care: Your personal care is a very private and personal affair but there may be elements you need help and support with, especially if you're unable to get to the bathroom.

Bed baths are great but as Danni says if it's not always practical then bath in bed wipes are a good alternative. They're large and designed for getting fully washed in bed – they also avoid the need to be dried afterwards.

Hair can be another issue, Danni went for the chop to make managing easier but there are options for keeping your hair clean. Dry shampoo works for a few days but isn't a long-term solution.

No rinse shampoos exist too to avoid excess grease or you can buy a shampoo cap. An inflatable basin is the best option for proper hair washing, along with lots of towels to ensure you don't soak your bed right through. A waterproof mattress protector is a complete essential and guarantees your mattress doesn't need replacing regularly.

Toileting in Bed: There are various toilet aids that can help in bed

Toileting is another personal care issue you'll need to handle and as Danni says for most people it'll mean using a bedpan or incontinence pads. It's not the most pleasant of issues but it is something you have to deal with. If you can manage a commode then this is a good option and there are personal toilets such as the Uriwell range which can be useful. There are a range of different bedpans on the market and as with the pillows it's worth finding out which is best to suit your needs.

Entertainments and Extras: **Keeping entertained and motivated is one of the main concerns if you're living from bed. Mental stimulation may not always be something you need dependent on your illness but keeping entertained is key to avoiding further problems such as depression.**

Danni highlights a laptop, tablet or internet connected phone as a hugely valuable resource as it gives you access to social networks, games and you can stream television and films. What works best for you will depend on the level of fine motor skills you have maintained and if you need further support your Trabasack and Media Mount combined can keep your tablet or smartphone perfectly in position.

A tablet is a great idea. You can watch films, talk to friends via social media and email and listen to music using something lightweight like a kindle fire. if you like to read as you can access the Kindle app and read to your heart's content when you're well enough. If you are reading a traditional book there is the Page Keeper that can help keep track and hold your page open. Danni also recommends the uniquely designed SleepPhones as they're designed to be worn in bed so extra comfortable.

Additional extra can include everything from an eye mask to make sleep even more restful to fans to keep you cool in summer, which can be no mean feat when living from bed. Other gadgets you could consider include remote controlled lights and electric switches and this makes another job which you may have relied on others for something you can do yourself.

The Most Important Point of All:

Taking Danni's word once more: *Try to remain positive. Living in bed is not the end of the world. It may not be what you choose but it doesn't have to be completely negative. I find joy in many things while being in bed, and though I do want to get out and back into my wheelchair, it hasn't been all bad. Bringing my computer in here so I could use it in bed was one of the best decisions we made.*

Caroline's notes: I recently got an electric hot water bottle off Amazon, much safer, charges in 15 minutes! It costs £24. I use a bolster pillow in bed for my shoulders and knees. An Occupational Therapist recently took me through 4 drawers worth of kitchen, bedroom and bathroom equipment, full of helpful gadgets you'd wish you'd known about before (you have to purchase them yourself, but they are handy to get the feel of, and they have several versions usually). Ask your GP for a referral. Our local Bury and Bolton M.E clinic also has an O.T.

Action for ME Welfare Advice

I spoke with Action for ME's Sonya Chowdhury and their welfare advisor Sarah, during a conference call they held on about benefits, which was very helpful.
They told me they have guides on benefits on their website, free to download, but also available in print: http://www.actionforme.org.uk/get-informed/publications
They include: PIP, PIP appeals, ESA, ESA appeals, etc. These are good to use with the Benefit and Work guides we can provide. They also have guides for employers and employees for in the workplace. AfME also produce short factsheets, like help for students.
I was also informed their Welfare Advice line is now available to everyone, not just their members.
Their Welfare Advice and Support Service provides information and advice on welfare benefits, Disability Discrimination, employment and insurance issues. Tel: 0845 122 8648
Monday 10am to 12.30pm and 2pm to 4pm, Tuesday 10am to 12.30pm and 2pm to 4pm
Wednesday 2pm to 4pm, Thursday 10am to 12.30pm and 2pm to 4pm
The line is always closed on Fridays and Bank Holidays.

If your GP refuses to write you a letter, or if it is their surgery's policy, write this on your form. (They are legally obliged to fill in ESA forms if the DWP write to them though). You can also get supporting letters from friends and family. If it's not possible to ask them or

they don’t feel able to write one for you, you could ask past employers, religious clergy, charity workers, etc.
If you don't qualify for any of the descriptors of the support group for ESA, look at Regulation 35. Regulation 29 is for the Work Activity Group. These regulations state that if found fit to work, it would harm your physical or mental well-being. More details about these regulations are in the Benefit and Work guides or AfME guides.
To get copies of the Benefit and Work guides, see page 3.

Delayed Recovery Of Muscle Strength

Reprinted with kind permission. First published in Breakthrough magazine Spring 2014, from ME Research UK.

The fact that muscles take longer to recover after exertion is characteristic of ME/CFS. In fact, the term myalgic encephalomyelitis (ME) originally referred to a potentially chronic disease characterised by profound, generalised, post-exercise loss of muscle power (fatigability); and, even today, the UK’s NICE Clinical Guideline insists that GPs should look for post-exercise symptoms before making a diagnosis.
However, experimental studies showing a loss of power after exercise have been few and far between over the past 30 years, which is why the new scientific paper from Kelly Ickmans, the ME Research UK research fellow at Vrije Universiteit Brussel, is particularly welcome.

In her report in the European Journal of Clinical Investigation, Kelly points out that muscle recovery in the upper limb has never been subjected to detailed research in ME/CFS patients, even though they complain of muscle fatigue in the arms and use these muscles most frequently for everyday activities such as combing and washing hair, ironing and cooking. So, Kelly decided to test muscle function in the upper arm during and after exercise using a simple hand dynamometer which measures force and strength.

The participants (48 ME/CFS patients and 30 healthy, inactive control subjects) were instructed to grip the dynamometer as hard as possible several times to obtain a pre-exercise ‘isometric maximum voluntary contraction’ value for their non-dominant hand (usually the left). After this, they performed an exercise challenge of 18 maximal contractions, and the recovery in muscle strength was measured over the next 45 minutes.
As the graph below shows, she found that muscle recovery was significantly slower in ME/CFS patients than in healthy people (muscle strength was still recovering 30 to 45 minutes after exercise). However, this was only true for patients who also fulfilled the 2010 criteria for fibromyalgia; i.e. who had
a high degree of “widespread pain” as well as other symptoms shared with ME/CFS.

As 43 to 70% of ME/CFS patients also meet the criteria for fibromyalgia, this test could be a low-cost, easy-to-perform way of objectively measuring delayed muscle recovery in a substantial number of people.

We’re still not sure why upper limb muscle recovery is delayed in patients. It may be that intracellular acid, which builds up in muscles during exercise, is removed less efficiently, as previous ME Research UK- funded research in Newcastle has suggested (See Breakthrough, Autumn 2011). Again,
the problem might lie with the circulation, particularly the microcirculation consisting of the smallest vessels, which impacts upon the muscles’ ability to remove waste products.

Whatever the underlying physiological reasons for the delayed muscle recovery, Kelly recommends that ME/CFS patients make sure to alternate between physically and mentally demanding tasks in their everyday life, and that they remember not to perform the same physically demanding task for extended periods. Importantly, she points out that these recommendations should be respected by healthcare professionals working with ME/CFS patients.

Non de Plume - Date bread cake.

Dates have particular symbolic meaning for those originating from Asia and the Middle East. But it is during this month of Ramadan, that they hold the greatest of reverence. The practice encourages a 30 day period of contemplation, when luxuries are denied in favour of staples that will simply sustain good health and allow each faster to maintain this annual observance of prayer and basic daily function. Food is a very important consideration at this time, and it is whole foods such as lentils, rice, bread and seasonal vegetables that are most relied on. The rich luxurious quality of a date may seem a little out of place amongst these more stoical produce, but it is a perfect food to consume when breaking one's fast at sunset. Apart from the nutritional quality, it is the toffee-like taste and soft gooey texture of a date that gently entices and rewards ones tastebuds. They are most commonly eaten whole rather than combined within a recipe. I am supposing this is more out of convenience than anything else. But sometimes we can appreciate the very best of something when it is involved in a collaboration.

Dates with brown sugar, bananas or walnuts: somehow each of these parties helps to support the qualities of the other. And I would imagine that for some amongst us, it is support and quiet care that will be most appreciated for the challenging month ahead.

- 1½ cups of boiling filtered water
- ½ a cup of warm rose water
- 300g of pitted and chopped organic dates
- 200 grams of sieved organic plain flour
- 1 tablespoon of baking soda
- 1 teaspoon of cinnamon powder
- ¼ teaspoon of sea salt
- 50 grams of organic brown sugar
- 1 teaspoon of organic apple cider vinegar
- 300 Mls of unsweetened almond or soya milk
- 100 Mls of melted organic coconut oil
- 1 tablespoon of flax meal mixed with 3 tablespoons of warm water left to thicken for a few minutes
- 200 grams of toasted chopped organic walnuts
- 9 x 5-inch greased baking tin.

Preheat your oven to 350° F and grease your baking tin. Pour the boiling water and rose water over the dates and allow them to steep. As the dates soak, sieve together the flour, baking soda, cinnamon, salt, and sugar. In a separate bowl, whisk the vinegar and non-dairy milk vigorously until frothy, add to this the coconut oil and flax meal-water mix. Now incorporate the wet ingredients into the dry. Drain then fold the dates and walnuts into the mix. Add a splash of almond milk if the mixture appears too dry. Pour the batter into the tin and bake for 35 to 40 minutes, or until the cake feels firm but springy to the touch.

Late edition – June 2014

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

A third of the people who believe they have CFS/ME may be suffering from a different yet treatable illness. Professor Julia Newton made the claim as she believes many patients could be suffering from Postural Tachycardia Syndrome (PoTS). PoTS is a disorder of the nervous system where symptoms include dizziness, rapid heartbeat, fainting, nausea, excessive tiredness and trembling. ME: one third of patients 'wrongly diagnosed' – The Telegraph – June 17

A feature on Robin Kaishek, who's been trained in the Prerrin Technique. The technique developed by Dr Raymond Perrin in Prestwich, involves removing harmful toxins due to inefficient drainage in the Lymphatic system. He also describes how pacing is important for patients as they have to readjust to their new lives. Beat Chronic Fatigue Syndrome with sense of balance and stability – Ham & High – June 12

A very well written account by Tess Dunford of her CFS/ME "journey". She describes how she went from being a very active person to someone who could barely work. She list the many treatments she's had, but believes strongly in time, rest and nutrition. She's also listed a number of points for patients to keep in mind with titles such as "Acceptance is key" and "Let it go". Running the chronic fatigue marathon – Stuff Nation – Jun 18

Let Your Light Shine is a new book by Dr Eleanor Stein. It contains methods for understanding and managing CFS/ME, Fibromyalgia (FM) and Multiple Chemical Sensitivities (MCS). The idea is to provide hope to patients who feel they are in a "dark place". Dr Stein said, "Our inner light is always there even on the "darkest" day. By the end of working through this manual I hope you will be better connected with your own light and that it will be shining brighter for you and those around you." Let Your Light Shine Through: A Valuable Resource for Patients with ME/CFS, FM and MCS– Prohealth – June 22

17 year old Rhia-Louise Nixon has CFS/ME, and throughout her education has been treated well by her teachers. However, she's classed as lucky because many schools judge sufferers on looks alone and some decide they are faking it in order to avoid school. It's a difficult situation for many genuine sufferers as they need a diagnosis from an understanding GP. Sufferers also need a school which is willing to help accommodate them. For example they could arrange regular home visits, have a scribe to write in exams etc. 'If an ME sufferer looks fine, the school assumes they are' – The Telegraph – June 14

Dr. Stephen Picca briefly covers how Fibromyalgia is diagnosed based on the patient's description of their symptoms (i.e. there is no scientific test). Fibromyalgia patients may also have 9 pairs of "tender points" in places such as the back of the skull and outside part of the elbow. Dr Picca also expresses regret at not being to answer and solve Fibromyalgia but does recommend many ways of coping such as practicing Tai Chi, having massages and taking Lyrica. Doctor's Diagnosis: Fibromyalgia – The Daily Apple – Jun 17