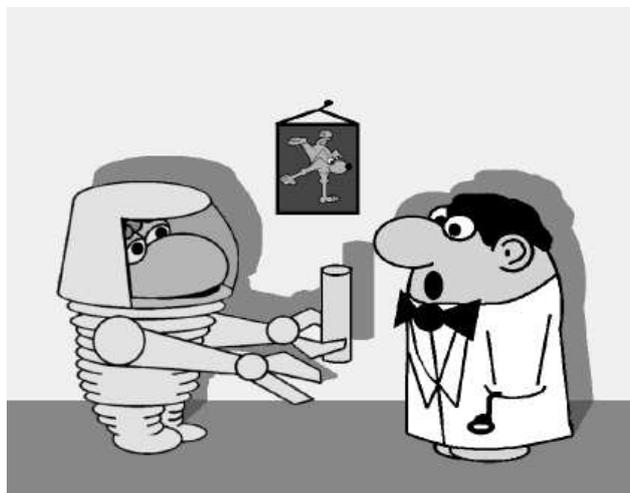




Welcome to Our May 2014 Newsletter

Note from the Editor Maxine: Thank you Caroline for stepping into the breach last month. I am healing nicely now and can do so much more than before the operation. I feel that I could go on a walk now but the consultant reminded me still not to overdo it! But I can drive again only short distances. I am glad to say the editor will continue to receive her copy of the news letter as I eventually remembered to pay my subs! This will be the last newsletter you will receive unless you have paid.



Oh, I see. You seem to be somewhat sensitive to the new drug.

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 May's Newsletter

Dates for your Diary	Page 2
Reminders	Page 3
Hydrotherapy	Page 3
Benefits & Work Guides	Page 4
A double-edged sword	Page 5
Laboratory muscle gym	Page 8
University of Liverpool Study	Page 11
Motability's show in Manchester	Page 11
Pain Toolkit	Page 11
Nom de Plume	Page 12
Late Edition	Page 13

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, 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. 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 15th May 7:30pm: Dr Raymond Perrin: Dr Raymond Perrin will be coming to talk about his latest research. Please note, this is our first meeting in the church building opposite. We are no longer meeting in the smaller church hall.

Thursday 19th June 7:30pm Tracy Hughes, Holistic Therapist: She does reiki and massage and has been recommended by members. She is based in Tottington.

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.

Yoga Classes: Are 3:15pm-4:15pm on Tuesdays at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Please arrive around 3:10pm. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Instructor: Julia Silver-Wren, email juliasilverwren@talktalk.net or 01204 394 768. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

Radcliffe Socials: The Sparking Clog is set to reopen after refurbishment at the end of April, so all being well, our next Radcliffe socials will be on the first Wednesdays of the month again- **Wednesday 4th June at 2pm**. The Sparking Clog has ample parking and is wheelchair accessible. We will put our newsletter on the table, so you can recognise us. The address is Moor Road, Radcliffe, Bury, M26 3WY.

Prestwich Socials: Attendance has picked up in recent months at the Prestwich socials. Maybe because there are have no Sparking Clog socials in Radcliffe whilst they undergo their refurbishment, or the danger of them stopping have increased attendance. Now the Clog socials have started again, we will see how attendance at Prestwich continues. **Please note change of venue to The Church Inn, 40 Church Lane, Prestwich, M25 1AJ. This has level access and free parking outside.**

May's meeting is provisionally set for the usual second Wednesday of the month- **Wednesday 11th June 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.



Supported by

**Bolton
Council**



Reminders:

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

Also our Facebook page just for members is www.facebook.com/groups/buryboltonmecs/
Don't forget our own web page <http://www.mesupportgroup.co.uk/>

Radar keys: We have Radar disabled toilet keys available at cost (£2.35, plus 50p if posted, or you can pick up at our Harwood meetings). Small headed or large headed (for those with dexterity problems). Contact Caroline on 01204 525 955 or email caroline@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.

Helpful GP's: Don't forget, we have a list of helpful GP's! There are only 13 on it at the moment, but 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.

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.

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.

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. Please send your contributions to: maxine@mesupportgroup.co.uk.

Hydrotherapy sessions: Preston and Chorley Fibromyalgia and Chronic Pain Support Group have kindly offered to let our group attend their hydrotherapy sessions on a trial basis for 3 months. If successful, we can consider carrying it on long-term.

Hydrotherapy (aquatic therapy) is physiotherapy treatment in water, instead of on dry land. Water provides buoyancy, which relieves the stress on weight bearing joints and allows movement without the impact of gravity. The resistance can also be used to challenge

muscles. Hydrotherapy can help ME/CFS by aiding in pain relief, easing muscle/joint stiffness, strengthening muscles, and also improve relaxation, well-being and quality of life.

The sessions are 12pm-1pm on the first Friday of the month, at the Jubilee Centre, Bolton. It is £3 per person and carers are free.

The sessions will be on: **6th June, 4th July from 12-1pm.**

Their group private hire the pool and changing rooms, so it is a lot quieter than when the pool have sessions open to the public. 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.

It would be good if you had physiotherapy exercises to do in the water, or just paced up and down a few times. Also, take a drink for afterwards and have a bit of a rest before you go home if you need it. At first, perhaps limit yourself to 20-30 minutes in the water to see how you go on and your symptoms are afterwards. I know from experience that it is quite difficult to get a hydrotherapy referral, so this is an excellent opportunity to try it out.

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.

Benefits & Work Guides

The guides are created by a welfare rights expert and a barrister. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal.

The group's subscription allows us to make these guides available to our own members for FREE. If you can get to our meetings, socials or yoga classes, you will be able to pick the guides up in person. Alternatively we can email them to you - if you do not have internet access yourself, perhaps a friend or relative could help out.

Please note that we will only ask you for a donation if we need to post the guides out to you, because some of the guides are rather lengthy (number of pages in brackets below) **Please return the guides to us if you can, as they are expensive to print and very popular!**

Please look through the list below and if you need anything phone Ruth on 0161 766 4559 or email ruth@mesupportgrop.co.uk

DLA & AA. No one can make a fresh claim for DLA, if aged 16 or over. They must apply for PIP.

Claiming Personal Independence Payments (PIP) (70)

Guide to PIP Appeals (19)

Attendance Allowance claims on physical health grounds (44)

DLA claims for adults on physical grounds (61) and/or mental health grounds (53)

Disability Living Allowance claims for children on mental/physical grounds (67)

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

The best possible way to challenge a DLA or AA medical report (28)

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

Appealing against a DLA decision (19)

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

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

DLA adult renewal claims on physical (58) and/or mental health grounds (50)

Changes of circumstances for people claiming DLA (8)

Employment Support Allowance

Being transferred from Incapacity Benefit to ESA (22)

Understanding ESA (42)

ESA claims for mental health difficulties (86)

ESA claims on physical grounds (84)

ESA appeals (39)

Permitted Work (6)

Pathways to Work Interviews (10)

Other

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)

Which benefits can I claim? (9)

Reasonable adjustments: Employers and Jobseekers (9)

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

Getting help with your benefits (12)

A double-edged sword

This article is taken from *InterAction* 86, the membership magazine of Action for M.E. www.actionforme.org.uk. Reprinted with kind permission.

Coping with getting older when you have M.E. can be extra challenging. Sylvia Kemp hears from people with M.E. aged 60 and over about this double-edged sword.

Getting older brings its own challenges. Things ache that didn't ache before. We can't always eat the things that we once did without suffering afterwards. We slow down a little, sometimes a lot. But we are not alone. Our friends and colleagues are in the same position so, as long as we can keep up with them, we feel we are doing alright.

But coping with getting older while also having M.E. is another matter entirely. Midge Gourlay, 67, has been ill for 30 years, severely for the first 10. She says, "Now I class myself mild and feel I have become younger. I knew what it was like to be old and disabled at 37."

An Action for M.E. Member, 60, who wants to remain anonymous says, "I mix with people my age and a lot older, and am finding it very frustrating that people seem to minimise my difficulties because they now have some themselves. I feel that all my years of illness have been invalidated, made unimportant."

As reported in *InterAction* 84, a study funded by ME Research UK has found that M.E. may have a different underlying disease process in older patients, who were found to have more fatigue than younger patients, and a "a significantly greater burden of autonomic dysfunction" (ie. affecting the body's ability to conserve energy and respond to stressful situations).

Along with the physical impact, the study also found that older people with M.E. experienced more depression and had a poorer quality of life. M.E. Friends Online forum user S, almost 62, has had M.E. since she was 54.

“M.E. is an isolating condition,” she says. “Advancing years can bring a greater sense of that generally anyway as children have their own lives, probably further away. Activities which would normally stimulate and reduce loneliness exhaust us.”

She also refers to the lack of romantic and intimate relationships that this illness often leads to, yet another loss that many have to try to come to terms with. She concludes, “I am lonely, aching to walk and climb like I used to and dance with someone special and feel part of life, not largely a spectator.”

Frances D, 79, agrees. “I find myself becoming quite depressed at times,” she says. “I wish I could find other people in my age group to chat to. Simply, I do not cope very well and find myself living a life of quiet desperation. But as that sounds rather negative I will try to be a bit more positive. “I have been affected by M.E. for nearly 24 years. During that time I gradually managed to come to some acceptance of my condition with the help, mainly, of various complementary therapies and the support of my husband, who sadly died nine years ago.

“Since then I have down-sized from a large, four-bedroom house to a small flat in a block designed for over 60s. This has been a good move in many ways, bringing me a lot of social contacts and new friends at a time when I was in danger of becoming isolated.

“However, because there is a lot going on socially here I have been in danger of taking on too much of the kinds of things that I enjoy doing and am good at but which, however enjoyable at the time, cause an increase in the M.E. symptoms. This is a problem that I never dreamed would have happened to me, after years of having to live a rather quiet life. It has also been brought home to me just how slowed up I am when I see other residents a lot older than I being so much more active.

“So what do I do about it? I think I just muddle through a lot of the time. However, when I am able, certain things are helpful [see ‘Practical tips and advice,’ below].”

After hearing these experiences, it strikes me that, while M.E. affects so many people in the UK, there is a lack of knowledge outside of the circle of those directly affected. Age UK list other illnesses such as MS, arthritis and Parkinsons, but M.E. remains a mystery to many.

I think that the problem lies mainly with the nature of the illness. It leaves many of us with so little energy to spare that we do not have the ability to bang the drum, fly the flag and generally make others aware that we are here and of what we need.

One way of getting in touch with others who understand is to contact your local M.E. support group. You can do this via Action for M.E.’s service directory (see useful contacts). Age UK (see useful contacts) offer befriending services for older people who are feeling lonely.

If you are well enough to have visitors, they can send a volunteer to your home, or have someone call you on the telephone each week to see how you are doing. If you have access to the internet – and if you don’t, try Action for M.E.’s factsheet, An M.E.-friendly guide to getting online – you could join an online community such as M.E. Friends Online or Gransnet (see useful contacts).

Gordon Littlejohn, 84, was diagnosed with M.E. about 12 years ago, but had been ill a decade before this, though previously very fit. He played rugby in his youth, ran marathons in middle age and says he used to be “a workaholic: the consultant who finally diagnosed me recognised this, and told me to pace myself.”

Now classifying himself as mildly affected, he believes “that it is vital to keep as fit as symptoms allow, given the restrictions that M.E. places on one, because once lost, it is impossible to fully regain. I believe that pacing is key, and cutting out the things that you know are harmful.”

For Gordon, the emotional impact of M.E. has been as significant as the physical. “My biggest mental problem is my loss of selfconfidence,” he says. “From the very beginning I always serviced my own car. In those days I could strip an engine or gearbox down to the last nut and bolt. Now the simplest job worries me. To get over this, at least partially, I just have to say to myself that I did it before, no problems, so what is the difference now? I get stuck in, and once I have started, I wonder what all the fuss was about.

“I try to keep my mind active by doing Sudoku and Enigma/ Codebreaker puzzles. When it comes to reading I have given up on books of physics and modern quantum theory – by the time I have got to the bottom of the page, I have forgotten what is at the top. My memory has never been particularly good, but now, short and middle term, it is dreadful.”

It is obvious from all of these comments that there is a wide range of views about how the illness affects us as we age. There is also the awful spectre of loneliness, so poignantly expressed above. Where older peers can join clubs, go on holidays and enjoy retirement, these things are not possible for many who find their energy levels only allow them to survive from day to day.

On the positive side, there is the prospect of a pension to free us from the struggle to obtain benefits or to cope with work when we are ill. We can look back on the things that we have been able to do before becoming ill, such as having relationships, children and careers.

Sheila Carroll, 64, got M.E. at 50. She highlights the problems of sensitivity to medications experienced by many people with M.E. when often, as we get older, we need more medication to keep us going.

However, Sheila has found some benefits, too. “My M.E. ‘divvy Dora’ episodes can, in later life, be laughed off as senior moments,” she says. “And I was actually relieved when I reached 60 and was entitled to a state pension. No more of those dreaded forms and medical examinations to prove I was ill enough to get Incapacity Benefit. I also have a bus pass so I can let the bus take the strain on tired days.”

I contacted Age UK and also my local Disability Advice Bureau, to enquire if they had any specific advice or services for older people with M.E. I was not surprised that the answer from both was no.

Age UK (see useful contacts) do have factsheets which give advice on an extensive range of topics, which would be helpful to many older people, whatever their health issues. These include claiming benefits, making the most of the internet and adaptations to your home. They can be accessed from Age UK’s website or from any Age UK office.

Several of those who contributed to this article are interested in getting in touch with other older people with M.E. If you're interested, email or write to Box No 4908, Action for M.E., PO Box 2778, Bristol BS1 9DJ.

Practical tips and advice

From NHS Choices (www.nhs.uk):

- When you reach the age of 60, you can get NHS prescriptions and NHS-funded sight tests for free. The annual flu jab is free once you reach the age of 65.

From Frances, who shares her story above:

- I say no, firmly but with a smile, when asked to do something I know won't be good for me. This gets easier with practise.
- Having said I would never be seen dead on one, I bought a second-hand mobility scooter which has been extremely helpful in allowing me to reach places I could not reach on foot.
- I hate having to rest on the bed during the day so I try to use meditation as an alternative. Sometimes it works, but not always.
- A recent helpful discovery has been to add a small teaspoon of sugar to a cup of tea about 4pm when fatigue can be particularly troublesome. This is after not adding sugar to anything for the past 40 years!
- If too tired to cook a meal I have a stock of delivered ready meals in the freezer.
- I have found that having things on wheels is a huge help. I have a few small trolleys which are very useful for keeping things handy instead of storing them away in cupboards so that I can do odd jobs sitting down.
- I use a shopping trolley to walk to some nearby shops and find it a huge help for walking and it stops me carrying heavy items.
- Cheap plastic baskets are ideal for storing things away in the fridge and in hard to get at kitchen cupboards. I know all this is probably what many older people do anyway but I think it is important for people with M.E. especially if living alone as I do.

About the author

Sylvia was diagnosed with M.E. in 2007. She retired from her job in local government and now runs a creative writing group within her local U3A. She is currently working on a spy thriller after last year publishing her first novel, *Fair Weather*.

Useful contacts

Action for M.E. services directory, Tel: 0117 927 9551, www.actionforme.org.uk

Age UK, Tel: 0800 169 6565, www.ageuk.org.uk

Gransnet, www.gransnet.com/forums

M.E. Friends Online, www.actionforme.org.uk/me-friends-online

Laboratory muscle gym.

This article is taken from InterAction 86, the membership magazine of Action for M.E. www.actionforme.org.uk. Reprinted with kind permission.

Using cutting-edge technology, Prof Julia Newton's team in Newcastle may have found out why the muscles of people with M.E. respond badly to exercise, and are searching for drugs that could help.

The story begins a few years ago when Prof Newton's team looked at what was happening in the muscle cells of M.E. patients as they exercised.

They used MRI scanners – previously used to look at brain structure and functioning – to measure the pH (acidity) of patient's muscle cells while they exercised their leg muscles inside the scanner.

They found clear evidence of acid accumulation in muscle cells. Such 'acidosis' happens in healthy people when they exercise beyond a limit, and crucially is associated with fatigue. But there was little acidosis among healthy controls during these modest exercises (three minutes of repeated foot-flexing against a light load).

The studies also found that as well as accumulating acid much faster than healthy controls, M.E. patients took longer to clear the acid that did accumulate when exercise had finished. The resulting fast and prolonged acidosis could explain some of the fatigue M.E. patients experience.

Using MRI scanners to look at exercising leg muscles in M.E. was a first. Now Prof Newton and colleagues have taken things to a new level in a study funded by Action for M.E.

Using muscle biopsies from ten of the patients who had taken part in the earlier MRI studies, they grew those biopsy cells to create little muscles in the lab. With sophisticated equipment, they created a 'muscle gym' that exercises these cultured muscle cells with electrical pulses.

The team then carefully developed an 'exercise' protocol designed to replicate the typical on/off activity of an M.E. patient in the real world, rather than continuous exercise that would be closer to running a marathon. For good measure, they checked biological markers to show they weren't, as Prof Newton puts it, "barbecuing the cells," confirming instead that the cells really were exercising.

Having developed a good 'real world' test in the lab, the team set about comparing patient muscles with healthy control muscle. They looked at an important molecule called AMP-activated protein kinase (AMPK to its friends), which plays a central role in ensuring the cell always has enough energy available.

In healthy muscles, they found a regular increase in AMPK activation in response to exercise: the more they exercised the cells, the higher levels of AMPK activation, just as expected. M.E. muscle cells behaved very differently, with no overall activation. This is a clear sign that cells in M.E. patients fail to respond to exercise by activating its energy supply system.

Further evidence came from looking at glucose, the main fuel for muscle cells. The more healthy muscle cells were exercised, the more glucose they took up, again as expected. But there was no increase in glucose uptake when M.E. muscles were exercised. Clearly something is wrong.

Taking a slightly different tack, the team looked at Interleukin-6 (IL-6), a cytokine that is produced by muscles in response to exercise. Again they saw a different pattern between patients and controls, but they noticed something else, too. The original MRI studies had found a difference in the way CFS patients' muscles reacted to exercise with two distinct subgroups, or phenotypes. The same two patient groups also reacted differently to IL-6.

This is a perfect example of what Prof Stephen Holgate (*InterAction* 85, p 4) has said about M.E. being a number of different illnesses: to make progress we need to find the different groups and see what's going on for each group.

Finally, the team turned their attention to the acidosis seen in the MRI muscle work. But first they had to find a way to measure acid within the cells. To do this they developed a pioneering system of nanosensors, tiny molecules that could be inserted inside the muscle cells, and light up at different acidity (pH).

Early results show that acidosis – too much acid – occurs in M.E. patients' muscle in the lab, just as it did in the muscles of the same M.E. patients when they exercised in MRI studies. Now that is an exciting result. But there's more.

At this point I'm afraid we need to look in a little more detail at how cells generate energy. As some will remember from biology at school (I didn't!), glucose is first converted to a molecule called pyruvate, which is centre-stage in this story.

Normally, pyruvate is used by the mitochondria (the dynamos of the cell) to produce energy as well as carbon dioxide, burning up oxygen in the process: this is why we breathe in oxygen and breathe out carbon dioxide. Not only does this 'aerobic' activity generate a lot of energy, it also doesn't generate acid.

However, the other possibility is for pyruvate to be converted to lactic acid – and too much lactic acid leads to acidosis. You also get very little energy out of the lactic acid route, and oxygen isn't needed: it is called anaerobic energy production.

Prof Newton's team think that in M.E., too much pyruvate gets turned to lactic acid and not enough gets burned cleanly by mitochondria. The result is not much energy, acidosis and consequent fatigue – which could explain a lot about M.E.

But why is this happening? It seems that in M.E. muscles, a key molecule (called PDK) is too active, which sends more pyruvate down the lactic acid pathway leading to acidosis and muscle dysfunction. Demonstrating the muscle abnormalities in cells in the lab is strong evidence against deconditioning as a cause of the illness, and of course psychological factors can play no role in these lab studies.

A drug called DCA blocks the troublesome PDK molecule, reducing lactic acid production, and early results indicate that DCA stops acidosis in M.E. muscle cells. The prospect of taking a pill to stop muscles playing up in M.E. is tantalising – but unfortunately DCA is toxic so it isn't a viable drug itself. Even so, the team now have a working system for testing possible drugs to use to treat muscle problems in M.E., and plan to look for other drugs that would have the same effect as DCA, but without the toxicity. Drugs that work in the lab muscle gym, and are known to be safe, would be candidates for clinical trials. This research has yet to be published but is expected to be submitted for peer-review soon.

This article is based on Julia Newton's very popular presentation to Action for M.E.'s 2013 research conference. You can watch this on our YouTube channel at www.tinyurl.com/actionformeyoutube

About the author

Simon McGrath became ill with M.E. 20 years ago. "During that time I have developed an interest in M.E. research and pursued my passion for Welsh rugby, both from the sofa," he

says. "These appeared to be lost causes for much of the time, but Welsh rugby has picked up and research looks to be heading the same way." You can follow Simon on Twitter @sjmnotes and read his blogs on Phoenix Rising at www.tinyurl.com/blogsbysimon

University of Liverpool Study Looking for Participants

Scientists at Liverpool are the first to implement a newly developed technique that is more sensitive to identifying mitochondrial function within the muscle's fibres. Researchers anticipate that these new methods will demonstrate whether skeletal muscle mitochondria in patients with CFS are dysfunctional, which would result in muscle fatigue and further complications leading to chronic inflammation and pain. The ME Association have put £30,000 towards this research.

Professor Anne McArdle, from the University's Institute of Ageing and Chronic Disease, said: "The mechanisms that lead to debilitating muscle fatigue and pain in CFS patients are unknown. "At Liverpool we have established newly developed techniques in the laboratory that can identify dysfunction as it occurs in the muscle cells. It is at this point we can look at interventions to reverse or halt further damage."

They have contacted us to put the word out about looking for volunteers. They said "In brief we are interested in the production of energy within the muscle and levels of inflammation in CFS patients vs. healthy controls. For the majority of volunteers involvement will simply entail a single visit to the Royal Hospital to donate a blood sample and complete a number of questionnaires. An additional component of a muscle biopsy and muscle function tests may be completed by willing patients."

Please contact Kate on 0151 706 4005 if interested in taking part or you have any questions.

Motability's show in Manchester

Hot off the press called Facebook. Caroline was just reading Motability's article on their upcoming show in Manchester on 16/17 May at Event City (opp the Trafford Centre).

Even if you don't get DLA/PIP mobility component, it may still be worth your while going if you are thinking of getting a more suitable car, a scooter or adaption, as there will be over 100 cars, from 20 manufacturers, over 40 scooters/powerd wheelchairs and 30 WAV's!

You can test drive cars as a driver or passenger. You need your drivers license if you wish to drive it. Also free face painting, balloon modelling, a mascot and a magician!! *squeal!!* That's only for the kids though unfortunately, I think. It's free, you don't need to book.

<http://www.motability.co.uk/whats-on-and-get-involved/one-big-day/the-big-event-eventcity-manchester-2014>

Pain Toolkit

The pain toolkit has been written by a GP who has lived with chronic long term pain, it is available to download FREE from <http://www.paintoolkit.org/>. They also have kits/booklets for younger people and teenagers.

It contains helpful tips on managing and living with chronic pain, like acceptance, pacing, etc.

The website also has videos, links to other helpful organisations, a newsletter, a place to ask questions and more. You can also buy an interactive workbook to download and use with a healthcare professionals, for £4.95. Thanks to Fightback for the tip.

The Pain Toolkit www.paintoolkit.org

Nom de Plume

Biscuit baby

Recently I received a request from a reader in need of a biscuit recipe deemed suitable to bake in the company of children. An interesting request as I have not shared a lot of time with children in my kitchen. Truth is I am fiercely territorial, a fact even my husband is reluctant to test. No matter how incapacitated I may be, there's never been a time I've ever wanted to be anywhere else.

I use my kitchen as a chemist or artist would use their work space, which means it is full of all manner of useful aids both Ad hoc and highly technical in nature. Following recipes alongside someone else requires two qualities which need to run simultaneously alongside one another, namely understanding procedure and having the confidence to be flexible. One needs procedure as a scaffold from which a degree of flexibility can be suspended from, otherwise the event will simply result in mishap and tedium.

On the rare occasions that my love and I have cooked together, I have assumed chief position as if steering the ship, with him in second command as he learns the ropes. And although each role has it's merits, nothing can beat being up early, alone in the kitchen as the morning light begins to flood the room. Simply put, I am lost and very unhappy without my daily meditation of kneading, stirring and chopping.

So for now I remain undecided as to if sharing my space would make me into a better or worse cook. But should the opportunity arise, I have no doubt that the proof will be in the pudding...

- 100g of organic desiccated coconut or ground almonds
- 75g fair trade caster sugar
- 1 organic large egg white
- 50g of organic toasted almond flakes
- Zest of an unwaxed organic lemon
- Extra small paper cake cases

To make the biscuits, preheat the oven to 180c/350f. With a fork beat the egg white lightly until small bubbles begin to appear. Place the coconut, sugar, and egg white into a bowl, stir thoroughly.

When evenly combined to a consistency that is firm yet slightly tacky, refrigerate. The mixture will be ready to cook with after 60 minutes, but will keep for up to 24hrs if need be. When ready to begin baking, place a generous teaspoon of the mixture into the palm of your hand so it can then be easily shaped into one of a collection of balls. Scatter the almond flakes onto a plate, and roll each ball upon them until completely coated. Site each ball within its own paper case. Line the cases on a baking tray that has been lined with greaseproof paper. Flatten each ball slightly with a wet fork and sprinkle with lemon zest. Bake for about 10 mins or until golden brown. For too long and they'll dry out, for too little and they'll be void of a crisp shell.

Cool completely on a wire rack before serving with lots of tea or better yet, a jug of homemade lemonade.

Note from Maxine – *how do I make the homemade lemonade?*

Late edition – April 2014

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

9 CFS/ME patients and 10 healthy people underwent a test and a questionnaire to assess levels of brain inflammation. The results showed that Neuro inflammation was widespread in the brains of the CFS/ME patients, and was associated with the severity of neuro-psychological symptoms. This is a big step to the understand of what CFS/ME really is, and it should lead to progress with diagnosis and treatment in the future.

Neuroinflammation in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: An 11C-(R)-PK11195 PET Study. - NCBI - Mar 24

The drug Agomelatine improves the perception of fatigue in people CFS/ME according to a recent study from Italy. Researchers found that the people who took Agomelatine had a significant reduction in perceived fatigue and an increase in their quality of life. The drug may be a future treatment for CFS/ME, although more research needs to be done before it becomes available. Drug Improves Fatigue in Chronic Fatigue Syndrome – About.com - April 14

Nancy Blake, author of A Beginner's Guide to CFS/ME, advocates a "light touch" approach to the treatment of the illness. She says a patient's situation needs understanding and they should be allowed to rest and progress at their own pace. Treatments should take place at home rather than having energy sapping visits to GP surgeries and hospitals. Finally a patient's employer or school/university should be informed so they can work with the person for a positive outcome. A Radical Care Pathway for ME/CFS – ProHealth – March 20

Research into Postural Orthostatic Tachycardia Syndrome (POTS) may have a parallel impact on the understanding and treatments for people who have CFS/ME. POTS is an autoimmune disease, and like CFS/ME there's often an infection which came before it. More research is being planned to develop a blood test and develop drug treatments. Problems Standing? Studies Suggest Autoimmunity Causes Orthostatic Intolerance: Implications For Chronic Fatigue Syndrome – ProHealth - April 29

Dr. Robert Shmerling briefly explains that Fibromyalgia "is a condition of unknown cause, a rather mysterious condition. The cause is chronic pain, long-standing pain, and it's body wide." Diagnosis is hard because you have to exclude many other illnesses before you decide it's Fibromyalgia. Treatment depends on the individual and usually involves different medical experts. The doctor recommends regular exercise as the most effective form of treatment, but also recognises the emergence of alternative therapies such as Yoga and acupuncture which can help. Fibromyalgia -- what is known and unknown – WVRO Public Media- April 27

Dr Leonard Jason recently presented a conference talk on the various definitions of CFS/ME and how a standard definition is so important for researchers. It's about making ME/CFS understandable and above all 'studyable'. It also provides a common baseline from which studies are conducted. Defining Moments – Dr. Leonard Jason on the House of Cards in Chronic Fatigue Syndrome – ProHealth - April 30