



Connect

The Hampshire Friends with M.E. Newsletter

(incorporating The Isle of Wight)

Patron: Elizabeth Turp

www.friendswithme.org.uk

Issue 88

Winter 2017



This year, while planning all the Christmas gifts you'll be giving, take a moment or two to consider how you could share that generosity with yourself. I'm not suggesting you spend money on a material present - although, if you can afford it, by all means go ahead and remember to wrap it beautifully! I'm talking about making an effort to gift your body with some extra self-care so you can enjoy the festive season without undue stress or too much physical payback.

If you feel guilty resting or pampering yourself when others are rushing around, remember that self-care can actually be a selfless act. You'll be happier company for those around you the less physically compromised or emotionally stressed you are.

Christmas shouldn't be a time of guilt so don't pressure yourself to carry out festive tasks just because tradition dictates it or you think others will expect this of you. It is a time of joy, peace and love in the darkness of winter, wherever and however you choose to express this. Perhaps you'll find that it's time to adapt family traditions or to create new ones that suit your body's requirements.

Best Winter Wishes,

Germaine

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COPY DEADLINE FOR NEXT NEWSLETTER:

February 20th 2018

Please email your newsletter contributions to:

editor@friendswithme.org.uk

or: HFwME Newsletter Editor, The Community Centre,
Brinton Lane, Hythe, Southampton, SO45 6DU

Disclaimer: Any views printed in *Connect* do not necessarily reflect the views of any of the national ME organisations or of *Hampshire Friends with M.E.*

We do not recommend treatments although some contributors may express an opinion. We recommend that anyone considering using an alternative treatment/therapy consults their GP first.

HFwME Comittee

Chairman:	Jenny Rogers
Treasurer:	Hui Min Tseng
Administrator:	Mary Franklin
Secretary:	Linda Clarke
Fundraising Officer:	Becki Field

HFwME Trustees: Nick Farrar, Jenny Rogers, Hui Min Tseng, Mark Rogers and Philippa Reece.

Registered Charity Number:1101610

Notice Board

Feel Connected!



Our "feel connected" service offers confidential telephone counselling (6-10 sessions) with a qualified counsellor. For further information, or to refer to the service, please email membership@friendswithme.org.uk.

A Warm Welcome

to our New Members



We would like to welcome all our new members to HFwME. We hope you find plenty of support and friendship and wish you many happy years as a member of Hampshire Friends with M.E.

Benefit Applications

If you're making a new claim, or renewing an existing one, for ESA and/or PIP remember to use the Benefits and Work Guides. You can download these from the Members' Area of the website or find them in the files section of HFwME's Facebook group.

A Big Welcome!



Jenny Rogers has taken over from Nick Farrar as Chairman of HFwME. Welcome to the position, Jenny! We all hope you enjoy chairing this charity.

Have You Visited the Members' Area of the website?

The Members Area is easy to navigate and provides quick access to lots of information including: details about group meetings, events, benefit guides for claiming ESA and PIP, and wellbeing resources.

You can also download and save a copy of the latest newsletter and contact list, update your personal details, and renew your membership by Paypal.

How to Log In

To log in to the members-only area, please go to www.friendswithme.org.uk and click on the 'login to the members area' button on the main page (the direct page address is <http://www.friendswithme.org.uk/wp-login.php>).

Click on 'log in with username and password'.

Your username / login ID is your first initial (capital letter) followed by your surname (lowercase). No spaces, no hyphen for double barrelled surnames. So, for example, if my name was Jane Smith-Jones, my login ID would be: Jsmithjones

Answer the silly sum so it knows you're human! Then click on the 'lost your password?' link and follow the reset password instructions.

Volunteer(s) needed for the role of Newsletter Editor

Editing the *HFwME* newsletter needn't be a lone responsibility. A shared editorship of the newsletter is an option so do express your interest even if you don't feel you could edit *Connect* solely by yourself. For more info, please contact Jenny Rogers via chair@friendswithme.org.uk

Advertising in Connect

A small fee may be charged for small personal ads. Businesses may place a whole or half page advert.

Contact Mary on 02380 841320 or e-mail mary.franklin@fiscali.co.uk for details.

Raise Money Without Parting With Extra Cash

Everyclick.com's 'Give As You Live' allows you to search the web, shop online, trade on eBay and raise money for HFwME without parting with extra cash.

Every search you make creates a donation. All searches, shopping and eBay activity made from www.everyclick.com/hampshirefriendswithme will raise money for HFwME.

Make sure you sign up so you can track your giving. It updates every three minutes and you'll be amazed how quickly it adds up!

HFwME News

Sunflower Competition Results

Linda C.

Thank you to everyone who entered the Sunflower Competition this year. We raised £104 in funds and had a few laughs along the way. I can announce that the winner with the tallest sunflower was Shannon Grierson with a mammoth entry of 10'2. This is excellent because it means I don't have to look for cunning ways to 'disqualify' the now runner-up Paul Knight with his 9'8 entry. Paul was the winner last year and we both thought it would be a shame not to have someone else taking centre stage this year, so well done Shannon for sparing us any dilemma! Debbie Knight should also get a mention for her 9'6 entry.



Trude with Tezza and Boris

Only one person subjected themselves to the humiliation of submitting a shortest flowering sunflower entry. Trude Chant is therefore awarded the Wooden Spoon for her dismal 98cm effort — a double-stalk of conjoined twins (Tezza and Boris) as she describes it. You don't get extra credit for producing two, Trude!

There were no 'biggest cheat' entries. Me digging up my sunflower root to add to the overall height was obviously a perfectly legitimate tactic — alas, even allowing for subsurface growth, my flower only measured in at 7'7. At least it survived and flowered this year; I took pride and enjoyment from that.

The winner of the craft competition was Laurel Wingfield who had clearly spent a lot of time and effort creating her masterpiece of a 170cm tall

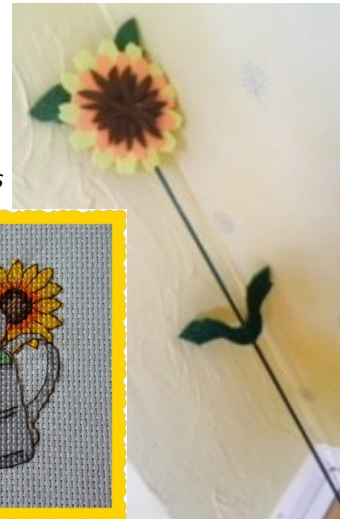


Shannon and her magnificent winning sunflower

freestanding sunflower made out of gold seed beads, material, coloured card, wire, a garden stake, copper wire and green hessian ribbon. To ensure the sunflower would stand upright, she even bought a Christmas tree stand. That's dedication!

Laurel may soon be moving away from the Hampshire area but I hope she'll be able to take her sunflower with her to remind her of some of the happy times she's spent with members of HFwME. I'm sure we'll all stay in touch via the Facebook group, but she will be missed by regular attendees at the Bellemoor.

Joint runners up in the craft competition were Sonya Green with a knitted sunflower on a stick and Julie Cody with a cross-stitch entry.



Julie and Sonya's craft entries



Laurel's winning craft entry



Well done to everybody who participated and thanks to everyone who took part and supported HFwME in this way.



Raised for
HFwME

Stepping Down as Group Administrator

Mary Franklin

After six years working for the charity I am giving up the Group Administrator role. This is part of the changes that are currently being discussed with you all. The committee are entering a period of reflection to see what the local CFS/M.E. community needs for the future and some of the ideas are explained in this newsletter.

Grant funding for my salary has been more and more difficult to obtain and, at the same time, the HFwME groups have been steadily declining. Although I am leaving this role, the committee and I are discussing whether I can work for the charity on an ad hoc basis, so it might not be a total goodbye!

I have enjoyed meeting and working with you all and I wish you all the very best for the future.

AGM Report and Changes in HFwME

Linda C.

HFwME's annual general meeting was held on the 18th of October at the Thornhill Baptist Church. We had members attending from Portsmouth, Winchester and Southampton. The five existing trustees were re-elected, namely: Nick Farrar, Jen Rogers, Hui Min Tseng, Mark Rogers and Philippa Reece.

With regard to the charity's main officers, the following people were elected into posts: Chairman - Jen Rogers, Treasurer - Hui Min Tseng, Secretary - Linda Clarke.

A vote of thanks was offered to Nick Farrar for all his hard work over the many years he has served as the charity's chairman.

There was a general discussion about the future direction of the charity, specifically with a view to the existing branch network and to membership renewals. A conclusion was reached on which the members voted unanimously. Further details about these decisions are given below.

Comments from the former chair, Nick Farrar, regarding the proposals discussed at the AGM:

"I agree with and endorse the various proposals that have been put forward. I think the proposals have been well thought through, and that what was outlined is the right direction for the charity at this time. Times and circumstances have changed since the early and middle

years, and even until relatively recently; but lack of volunteers and finances now have to primarily determine the direction of travel for the foreseeable future."

A Change To The Branch Structure

Due to a reduction in volunteer availability, HFwME can no longer provide a centralised branch network and regrettably a lot of the old branches have folded due to lack of regular attendance. Being tied to a set day and time is not always convenient to members. We hope that where any members are still informally meeting up in local areas, they will continue to do so. The HFwME website (www.friendswithme.org.uk) is in the process of being revamped and will feature a noticeboard to display notices about any events or meetings that members wish to organise and invite other members to attend. However, the emphasis will now be on members to make their own arrangements locally. To aid members in this regard, the contact list will be revamped and made available via the members-only section of the website. There will be more about this in the next newsletter, after Christmas.

Open Days

In lieu of regular branch meetings, the HFwME committee plans to hold open days in community centres across the county in the coming year. This is a new and evolving idea but we hope it will give new and existing members a chance to meet and get to know each other in a quieter setting than a noisy pub or outside location. It will basically be a workshop to answer queries and questions on any matters from benefits to mobility, from diet and supplements to pacing and symptom management.

These will be one-off events so we hope you will put them in your diary and do try to attend if you can. Exact venues will be confirmed in due course. We welcome any venue suggestions, feedback and ideas from members. Venues ideally needs to be quiet, cheap, have parking and public transport and hopefully be close to the major road network. See the events calendar on page 6 for current planned open days.

A Change To The Newsletter

Germaine Hypher is stepping down as our newsletter editor after many years of producing what, I'm sure we all agree, has been an exceptional read. We are still looking for a replacement volunteer to take up the role. In the meantime, after Christmas, the committee will produce the next edition which will heavily feature the changes we will be making to the website.

HFwME News

changes we will be making to the website.

We hope that members will continue to submit articles and helpful information to: editor@friendswithme.org.uk, which we can display in either the members-only or the public sections of the website. We realise that information on websites is not as convenient as a downloadable newsletter but, without an editor, this may be our best option. The website should act as a library of content and we believe there is much of benefit that we can add to it in the coming months. We will post updates so you can easily find out what's new.

Our Facebook Group

People have recently queried the old policy that allowed people to join our Facebook group for a month's free trial before deciding if they want to join the charity as a member. This policy was discontinued many years ago for a couple of reasons. Firstly, since it is very easy to create a false Facebook identity, anyone could join the Facebook group, befriend our members and then continue making individual contact without ever needing to actually join the charity. Not only did that deprive the charity of their joining fee (which in future will be our only source of income other than members' donations), it meant they were never required to give genuine addresses or personal details. This could leave our members vulnerable. All new members will therefore continue to have to pay a joining fee before being added to the Facebook group.

Members won't be able to add new people to the group themselves. If the person you want to add is a family member or primary carer, please contact membership@friendswithme.org.uk, otherwise please ask anyone you think might be interested in to register with us by visiting our website: www.friendswithme.org.uk/join-us.

We'd like to thank Julie Cody for volunteering to be our Facebook moderator, together with support from Roger Griffin and Trude Chant. Please help them by observing our Facebook code of conduct.

Administrative Changes at HFwME

Mary Franklin will be leaving us as Group Administrator at the end of this year. HFwME will no longer have a paid employee supporting the committee, and all charity operations will be undertaken by volunteers from now on. Mary has been an integral part of the committee since 2011 and we will miss her input and cheerful support. Unfortunately, this is now a necessary change. We hope she will continue to be involved with the charity on an ad hoc basis and perhaps also join us in a

member capacity at any future social events.

In an effort to reduce the administrative burden on the committee, the 0845 phone number and PO Box postal address will no longer be in operation. If you have a query or need to contact the committee for any reason, please use the membership@friendswithme.org.uk email address. It may take us a short while to respond, depending on the prevailing health of our volunteers.

The Ethos Of The Charity

Members' expectations of the charity may need to be revised. We are not a fully staffed NHS Service and all our volunteers are themselves ill with M.E. This affects our ability to respond and provide assistance to members. Therefore the emphasis of the group has to be on us helping our members to help themselves. HFwME can be of assistance as a self-help/information providing platform while also encouraging communication and contact between our members. Breaking social isolation is one of our core purposes; when the charity was formed, Facebook and social media did not exist. Now it creates very real opportunities and we must change the way we go about providing our services to reflect this.

Membership Fees and Renewals

We will no longer be asking members to renew their membership on an annual basis. The effort of sending out requests and reminders outweighs the benefit and response. However, without income, the charity cannot function. There are annual costs that have to be met, including insurance, website hosting and charity commission requirements.

If you value this charity and want us to continue to be able to reach out to support and help new members (including the newly diagnosed), **please consider making a donation**. Several members are now setting up standing orders with their bank to pay £1/month. Alternatively, an annual donation of the suggested £8.50 could be made on a date of your choice. All one-off donations are very much appreciated.

Donations can be made on our website, via Everyclick, by using the pink 'donate now' button on the right panel. In the near future, we will also be able to accept donations via PayPal on our website. You can send a bank transfer to the following Co-op bank account: Hampshire Friends with M.E. Sort code: 089299. Account number: 65706679. Please use your full name as a payment reference.

We are grateful for your continued support.

Events Diary



Secret Santa

Organiser: Roberta, whatabore@hotmail.com (please put *HFWME* in the subject line) Tel: 07486677997.

Details: If you've signed up and can't make the deadline or have any questions please contact Roberta.

Posting Deadline: Friday 8th December

Receiving Deadline: Thursday 14th December

Southampton Christmas Meal

Thursday 14th December, 1pm

Venue: Crafty Bug Café, Woolston, Southampton

Organiser: Lisa of the Crafty Bug Café

Cost: £7 at the door to cover teas/coffees and snacks. Soft drinks will be at an additional cost.

Details: Informal Christmas get-together. All welcome! No need to book but please register your interest to help Lisa have an indication of numbers. Hope to see some of you there.

2017 Open Days — Details TBC

Saturday 17th February, 12-3pm — Horndean

community centre. Merchistoun Hall, 106 Portsmouth Rd, Horndean, Waterlooville, Hampshire, PO8 9LJ

Saturday 21st April — Winchester

Saturday 19th May — Southsea/Portsmouth

Saturday 14th July — Southampton/Fareham

Saturday 8th September — Basingstoke/Odiham

Saturday 20th October — Southampton, includes AGM

Magnesium in Neurology and Emotions

Dr Sircus

A deficiency of magnesium can cause increased sensitivity to noise, nervousness, irritability, mental depression, confusion, twitching, trembling, apprehension, and insomnia. Magnesium is a premier medicine for depression, sleep disturbances, emotionally disturbed behavior, and neurological diseases because of its strong positive effect in calming and nourishing the nervous system.

If magnesium is severely deficient the brain is particularly affected. Clouded thinking, confusion, disorientation, marked depression are largely brought on by a lack of this nutrient and remedied when magnesium is given. Other symptoms of magnesium deficiency include muscle spasms, weakness, twitching, muscle atrophy, incontinence, nystagmus (rapid eye movements), hearing loss, and osteoporosis.

This is an extract from an article on www.drircus.com. Hampshire Friends with M.E. does not endorse any product, treatment, therapy or service.

Don't Judge as Good or Bad

Leo Babauta

*"There is nothing either good or bad,
but thinking makes it so."*

- William Shakespeare, Hamlet

One of the greatest sources of unhappiness, in my experience, is the difficulty we have in accepting things as they are. Without judgment, without wishing for otherwise.

When we see something we don't like, we wish it could be different — we cry out for something better. That may be human nature or perhaps it's something that's ingrained in our culture. The root of the unhappiness is that we decided we didn't like something. We judged it as bad, rather than saying, "It's not bad or good, it just is".

As you catch yourself judging, and wishing for different — and we all do it — try a different approach: accept, and understand. It might lead to some interesting results.

Surprise Surprise!

Louise McAllan

People will surprise you. And, as with all surprises, some will be pleasant and some... well... not so much.

Society is not geared up for the kind of chronic illness that lasts indefinitely and has no certain path. People are more familiar with a different pattern — someone gets ill then either recovers (quickly or slowly but with a definite upward trend) or is told they have a terminal illness. This kind of certainty is impossible with M.E. It might get better, it might get worse, or it might fluctuate wildly within the month, the week or even the day. And it will probably drag on for years. This can be difficult for others to understand and cope with.

When you are first ill people come to visit, send cards, offer to do shopping, make a special effort with social arrangements and generally offer support. But you carry on needing this long after most people would have recovered and it can be hard to ask for support or accept it when it is offered.

I am lucky to have had more good surprises than bad but still the thought of those who have let me down niggles at the back of my mind. I try to excuse them — they don't understand and my expectations of people have always been too high. In the end perhaps we were not friends in the first place as I had thought, but just acquaintances. I am glad to have found that out.

I try to dwell on the good surprises, the people who have been there helping me through, because they're the ones that matter.

Take Lots of Breaks to Get More Done

Jonathan Mead

This article wasn't written with M.E. in mind (it is reprinted, with permission, from zenhabits.net) but the wisdom is wholly relevant to sufferers of this disease so read on for some valuable tips.

What if you could get more done by working less? Everyone wants that, right?

But that's obviously not the way most of us work. We think that in order to get more done and be more productive, we need to increase our effort and time.

That's the obvious, intuitive answer. But the less obvious — the counter-intuitive approach of working less and taking more breaks — gets better results.

Instead of increasing the amount of time you work, try to increase the *quality* of the time you work. Focus on single-tasking and eliminating distractions. Train yourself to focus on *one thing* for a designated period of time.


Then focus on taking breaks that rejuvenate you and recover your ability to focus. You may be resistant to this idea at first; taking breaks is seen as lazy and counterproductive. Warriors push through and suck it up, right? Maybe, but they're also the ones with the shortest careers, who burn out the fastest.

By taking a relaxing and regenerative break *at least* every ninety minutes, you increase your capacity to do more work. Just like your muscles need to relax after they tense up, *you* need to relax after short bursts of focused work. Obviously you don't want to *only* take breaks. There needs to be a balance and a blend of relaxation and focused effort. But it's amazing how many people forget the relaxation aspect.

I used to be this way. I thought if I worked through lunch, took no breaks and just pushed through it, I would get more done. But what happens is that after a few hours I'm drained and lose the ability to focus. I end up multi-tasking, becoming easily distracted and default to doing unimportant busy work. I'm running on one or two cylinders instead of all six. But if I took short, rejuvenating breaks, I'd allow my body and mind to recover and regain ability to fire on all cylinders.

In short, when you don't take breaks and allow yourself to recover, you're less than 50% there.

It's obvious that taking short, rejuvenating breaks is the more effective way to work. So what are some



Sometimes the most productive thing one can do is to sleep.

examples of these types of breaks?

- **Change channels** Most of us do a lot of work on the computer, so doing some kind of physical activity for a few minutes can be a great way to change our state. A brisk walk or yoga can be a great way to get your body moving and put yourself in a different state.

- **Breathe** Do ten or fifteen minutes of meditation, focused on

your breathing.

- **Refuel** Eating some kind of snack or small meal every ninety minutes is a great way to keep your glucose and energy levels steady. Go for fresh, organic fruit or a salad to get a quick pick-me-up.

- **Power nap** A twenty minute nap in the afternoon feels awesome and rejuvenating.

- **Motivate** Take time out and listen to a guided meditation or personal development video on YouTube.

- **Flood your body with consciousness** This is something I've been doing lately that's been really working for me. Take ten minutes out to lie on your bed and focus your awareness first on your toes and feet, then gradually move your focus up through your body, into your legs, pelvis, torso, chest, back, shoulders, arms, hands and fingers. Then back up through your arms into your neck, up your throat and into your face and your head. Really focus on feeling the energy in your body and only move your conscious awareness up your body after you've really felt it in the last part.

- **Total relaxation** This is a follow up to flooding your body with consciousness. After you've completely immersed your body in awareness, focus on relaxing each muscle in your body. In the same way as previously, start with your toes and work your way upward through your body. Really let go and relax.

These are just a few ideas for ways that you can really relax, recover, and rejuvenate your body.

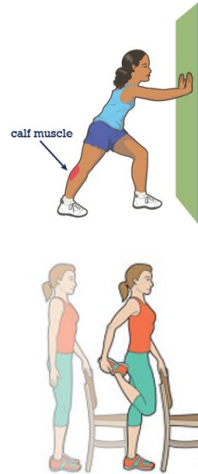
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Remedies for Restless Leg Syndrome

*Restless Leg Syndrome (RLS), causing twitching and an involuntary urge to move the legs, is a common symptom in M.E. patients. Some swear by the old wives' remedy of a bar of soap under the bed sheets to relieve it. Up until now, your editor's remedy of choice has been to stretch the calf muscles. There are many actions you can try but a report in *The New Scientist* suggests there may be a more entertaining way of preventing RLS from getting the better of you...*

RLS-UK (www.rls-uk.org) recommends the following tips for reducing RLS:

- Magnesium oil spray, used on the legs, is available from some pharmacies and health food shops. Check with your doctor before you start using this product.
- Eat food rich in folic acid, such as asparagus, spinach and kale.
- Supplements such as iron, vitamin B complex and calcium can help. Low iron levels may contribute to RLS so have your serum ferritin levels checked by your GP. It's important that you consult your doctor before taking supplements as excessive iron can be dangerous.
- Try to maintain a routine in the times you go to bed and get up.
- Keep your bedroom as cool as possible and try to use cotton sheets.
- Take regular moderate exercise. A gentle walk early in the evening helps some.
- If sitting at a desk or table, always ensure your feet can rest flat on the ground.
- Different practices before bedtime benefit some, such as a hot or cold bath, limb massage, or vibratory stimulation of the feet and toes.
- Eating a banana a day can help as bananas are full of potassium.
- Avoid eating late at night. If you have to eat later in the day, avoid stimulating or strong foods.
- Quinine or tonic water **doesn't** help RLS.
- Avoid or limit your intake of alcohol, caffeine and nicotine for several hours before bed.
- All of the drugs in the following list of the most frequently prescribed RLS medications carry risks of side effects but could help you in making informed decisions with your GP: Levodopa, Ropinirole, Pramipexole, Rotigotine, Pregabalin, Clonazepam, Gabapentin.
- Calf stretching: Stretch out your arms so that your palms are flat against a wall and your elbows are nearly straight. Slightly bend your right knee and step your left leg back, positioning its heel and



foot flat on the floor. Hold for twenty to thirty seconds. Now bend your left knee while still keeping its heel and foot flat on the floor. For a deeper stretch, move your foot back a bit further. Switch legs and repeat.

- Front thigh stretching: Standing parallel to a wall or a chair for balance, grab and pull one of your ankles toward your buttock while keeping the other leg straight. Hold for twenty to thirty seconds. Switch legs and repeat.

And now for the more... interesting... suggestion, as featured in *The New Scientist*:

“RLS is a distressing neurologic disorder characterised by an urge to move the legs. It is usually associated with unpleasant sensations in the lower limbs such as tingling, aching and itching.

Drugs that increase dopamine have been shown to reduce symptoms of RLS when taken at bedtime and are considered the initial treatment of choice. Although such drugs provided significant improvement of symptoms for a 41-year-old man with RLS, he found an even better treatment – complete relief after masturbation or sex.

Luis Marin and colleagues at the Federal University of São Paulo, Brazil, who reported on the novel treatment in *Sleep Science*, speculate that the release of orgasm-related dopamine might play a role in the alleviation of symptoms.

An orgasm provides one of the biggest natural blasts of dopamine available to us. When Gert Holstege at the University of Groningen and colleagues scanned the brains of ejaculating men, he said the resulting images resembled scans of heroin rushes. This temporary increase in dopamine may act in a similar way to drugs that mimic the hormone, granting the man in question enough relief from his restless legs to allow him a full night's sleep.”

Subsets, Subsets, Subsets

Cort Johnson

Everyone with M.E./CFS who's been around a bit must ask themselves at some point, "Do I have what she or he has?". Some people do great on treatments that others fail on. Some people get really, really sick while others maintain at least a modicum of health. The variety of symptoms, treatment responses, illness progressions, even illness triggers is astonishing. For every person who remembers the exact day their illness came crashing down there's another who doesn't remember the day, week or even month they became ill because their illness came on gradually.

There's the relapsing-remitting group which gets better and then worse, the plateaued group in which things remain much the same for decades and the progressive group where the illness gets progressively worse – sometimes to levels rarely seen in any nonlethal disease.

Most researchers concluded decades ago that M.E./CFS must be littered with subsets. Just what those subsets are is a critical question because, as Jared Younger notes, a treatment that works for one subset probably won't work for another.

Some subsets appear to be showing up. Dr Peterson's atypical subset typically has an unusual onset, an unusual course, has unusual comorbidities and is sicker than the rest of us. The immune systems of short duration patients (one subset) are on fire while the immune systems of longer duration patients (another subset) have run out of gas.

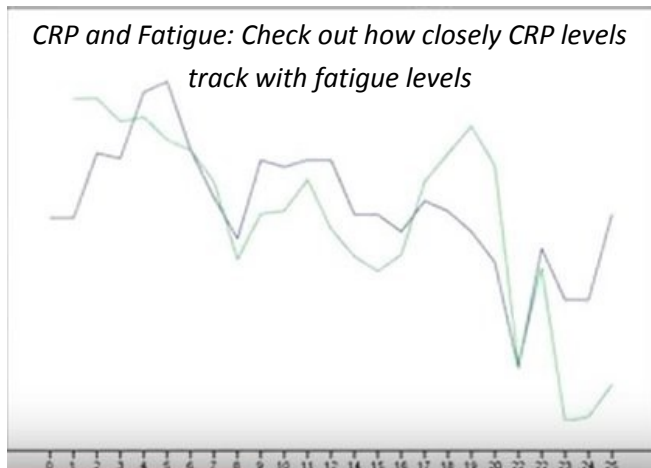
Jared Younger, in an unusual move, has released some early results from his big daily immune monitoring 'Good-day, Bad-day' study to spread some early news on his findings.

Younger's 'Good-day, Bad-day' study is an example of what the NIH does best: throw a boatload of money (more than \$1,000,000 over three years) at a complex study. Younger's study allows him to track which immune factors track with a person's fatigue. A substance that rises and falls depending on how fatigued a person is very likely has something significant about it.

The scale of testing is extraordinary. The study includes seventy people with M.E./CFS, twenty healthy controls and twenty fatigued people with thyroid issues. The

study involves twenty-five straight days of blood sampling from all 110 people, and each sample is tested for 51 substances associated with inflammation. If my maths is right, that's approximately 140,000 tests for inflammatory substances over the life of the study. Each person will also report their fatigue levels daily on a personal handheld computer. All this data will be thrown into a computer to see what patterns emerge.

It's still early yet – the study will run for several years – but, in his YouTube video, Younger reported that some patterns may be starting to emerge.



The Infection Group?

C-reactive protein (CRP) levels are tracking with fatigue in about thirty percent of the M.E./CFS participants. This suggests that a significant number of M.E./CFS patients may have an underlying infection that's popping out during their bad days.

A C-reactive protein is an 'acute-phase' protein produced by the liver which shows up early in an infection, in cancer or in response to a tissue injury. Once immune cells called macrophages come into contact with dead or dying (infected) cells they release a substance called IL-6 which triggers the production of CRP (and fibrinogen) by the liver. When CRP binds to the surface of those cells it gets the complement system involved which, in turn, helps more macrophages to find, engulf (phagocytize) the infected cells and begin clearing them away.

The key to high C-reactive protein levels is plenty of dead or dying cells – something which usually occurs in the context of some infection (bacterial, viral, fungal), inflammatory diseases, malignancy or injured tissues. A very large (n=1125) fibromyalgia study recently found increased CRP levels in FM. It's not clear how high the CRP levels in the M.E./CFS subset was relative to other diseases but what is clear is that the high CRP levels would probably be swamped by the lower CRP levels in the two other M.E./CFS subsets; i.e. CRP would not be elevated in the group as a whole.

Autoimmune diseases like lupus, scleroderma, polymyositis, and dermatomyositis, on the other hand, generally have little effect on CRP levels. (In fact, one researcher proposed that CRP protects against autoimmune diseases.) That brings up the next group.

The Autoimmune/Autoinflammatory Group?

A substance called fractalkine – which is elevated in many autoimmune and inflammatory disorders – is tracking with the fatigue levels of another third of M.E./CFS patients. Fractalkine, whose release is also triggered by damaged cells, promotes the production of pro-inflammatory cytokines.

Fractalkine is released by T-cells and other immune cells, endothelial cells and, most prominently, in the central nervous system.

In contrast to CRP, fractalkine is elevated in autoimmune diseases like rheumatoid arthritis, Sjogren's syndrome, systemic lupus erythematosus, and scleroderma, as well as diseases associated with systemic inflammation. In rheumatoid arthritis fractalkine directs immune cells to the joints. Fractalkine is also elevated in systemic inflammatory diseases like atherosclerosis and inflammatory cardiomyopathy.

Because fractalkine appears to be intimately involved in producing pathological pain, one wonders if these are the fatigue and high pain patients. One study has found increased fractalkine levels, not in the blood, but in cerebral spinal fluid in fibromyalgia. The study suggested that damaged neurons were triggering fractalkine release.

Because fractalkine plays a prominent role in producing inflammation, anti-fractalkine agents are being examined. Several existing drugs and supplements (baclofen, Apo-A1, resveratrol, epigallocatechin-3-gallate) may be able to suppress fractalkine production.

The Non-Immune Group?

In the last third of patients, Younger hasn't yet found a pattern, which suggests that the fatigue symptoms of this group may not be driven by the immune system. This, Younger suggested, could be a metabolic or other group.

Conclusions

Younger's 'Good-day, Bad-day' study is looking for biomarkers in an entirely new way. Very different from the one-time shots at assessing immune problems that we usually see, Younger's study is tracking immune changes as they occur over time and pulling out the immune factors shown to be most associated with fatigue. Many other symptoms exist in M.E./CFS, but as Dr Lerner used to say, when the fatigue lifts the other symptoms follow.

Thus far the study suggests that the fatigue in M.E./CFS may be produced differently in the three subsets of patients: by an ongoing infection in one, by an autoimmune or autoinflammatory process in another, and by something outside the immune system in the third.

The most intriguing thing about Younger's study is its intensity. No one has examined the immune basis of fatigue in M.E./CFS with Younger's intensity. It's no surprise, then, that Younger is getting results (CRP, fractalkine) new to M.E./CFS – results that also, interestingly enough, fit with what we already know. Infection and autoimmunity, after all, have long been thought to be present in M.E./CFS. Younger's early results suggest that they are present – but in different sets of patients.

If Younger's early results prevail and are validated we should ultimately see radically different treatments for the two different subsets – immune activators and anti-pathogen treatments for one, and immune suppressants for the other. We'll also see studies focused on each subset and that could make all the difference in research.

Cort Johnson has had M.E./CFS for over thirty years. The founder of Phoenix Rising and Health Rising, Cort has contributed hundreds of blogs on CFS, fibromyalgia and their allied disorders over the past ten years.

Comfort

Sarah-Louise Jordan

I don't know about you
But sometimes I feel like a wild rabbit
In a stranger's burrow
Trying to forget the sight of the teeth
Of a dangerous fox
Snapping as he chased me.

I let the darkness beckon me,
Shivering a little at the depth of it,
As I venture deeper into this unknown place.
I keep going and soon I am lost.
I almost believe I might never see a light again.
I feel alone,
Because these are the small hours when
Every frightening thing casts a shadow
Bigger than it is.

I go onwards, with my heart speaking louder
Than any other noise and soon the burrow
Opens out a little and there is another creature
One just like me, who I can sit beside;
We can give each other comfort.



Practicing Self-Care

Sarah-Louise Jordan

The best advice I've been given in the last six months is "practice self-care". It's a statement a lot of people have echoed and it is excellent advice. I'm pretty sure it's also something we find incredibly hard to do — we love one another and want to be there for all the people in our lives, to share the joys and help with all the sadnesses. We don't want to miss out on something wonderful and we don't want to be absent when we are needed either.

Often we don't have so much room in our lives for being there for ourselves. We rarely treat our own problems or sorrows as tenderly as we treat other people's.

This week I took a day to colour in fairies and sleep... not because my body demanded it but because my soul needed a little TLC. It was a bit of a revelation for me. It gave me more peace and it made me understand that when we take care of ourselves our capacity to care for other people is greater as well. If we are always running on empty there is less of us to go around! Like the difference between sharing an admittedly delicious little cupcake or having a whole giant Victoria sponge to work with.

I hadn't even understood that I tend to wait until my body is screaming at me before I allow myself a whole day of rest. I nap a lot every day, and I'm good about that, but I treat whole days of rest as emergency-only things. The result of which is by then I'm in too much pain and discomfort to even enjoy them and there's no chance of colouring in fairies at all.

So, whether you allow yourself a Self-Care Saturday, a Sleepfest Sunday or a Fairyful Friday, I hope you know that it's ok for you to take space for you as well. It is a gift to your wellbeing, and making sure you're ok is a gift to all of us, too. Not just because you'll then have more energy to deal with my tragic biscuit shortage crisis (or whatever else loved ones may require support with) but, more importantly, because we care about you, and seeing you extend your gentleness to yourself will make us happy.

Sarah-Louise Jordan is an M.E. sufferer in Surrey.

How you treat
yourself is how you
are inviting the
world to treat you.

The Importance of Vitamin D

with M.E./CFS and Fibromyalgia

Clarissa Shepherd

I've always stressed the importance of knowing what your vitamin D3 level is. This is so important for pain reduction (especially bone pain), vision problems, fatigue, and healing from infection.

Vitamin D3 plays an often under-appreciated role in the innate immune response, therefore helping reduce inflammation. This is the reason it helps to diminish pain.

Research has found that low vitamin D levels can contribute to developing diabetes because vitamin D helps the pancreas work properly. It can also prevent cholesterol from being within normal levels. The research also shows that without the proper amount of vitamin D weight loss is almost impossible. All of this really hit home for me.

I've had a very difficult time keeping my levels at a good place. If I get it up and then reduce to a maintenance dose it goes right back down. Those of us with M.E./CFS or Fibro are, most likely, deficient for we can't absorb it in the same way as someone who doesn't have chronic illness. Of all the people that I've encouraged to get theirs checked only two had a good level. Normal in the UK is between 70-140. A good level is around 90 to 110.

Always take vitamin D3 for best results and be sure, if you get on a high dose of vitamin D, to get it rechecked to find what dose is right for you and to maintain a good level. Many of us must take 5,000 iu to 10,000 iu a day in order to achieve this. You don't want it to get over the highest limit for that is a toxic level. Taking large doses is not toxic. It's only toxic if the level of vitamin D in your blood gets too high and stays there.

So get it checked and keep it at a good level in order to diminish pain, anxiety and depression; to increase energy levels; to be able to fight off infection; and for prevention of many diseases.

There are some illnesses and kidney issues in which you aren't supposed to take large amounts of vitamin D so please always check with your doctor.

Editor's Note: *Vitamin D is absorbed by the body from sunlight, even on overcast days. Sitting outside for just ten minutes can be beneficial. However, in the winter months, and especially for those confined to the house, it can be hard to get enough of this vitamin so do consider consulting your doctor about your vitamin D levels if you think this may help you.*

Hampshire Friends with M.E. does not endorse any product, treatment, therapy or service.

The Poet's Pocket

As I Lay Here

Rachel Harrison

As I lay here,
In this darkened room,
The wheels in my head slowly turn.

I feel lonely,
Yet I am not alone.

I cry silent tears,
Yet I am not sad.

I feel trapped inside,
Yet I am free.

I feel my heart breaking,
Yet I am loved and love in return.

I feel lost,
Yet I was found and protected long ago.

I feel weak,
Yet I know I am strong.

I feel tired daily,
Yet I am passionate and energetic about life.

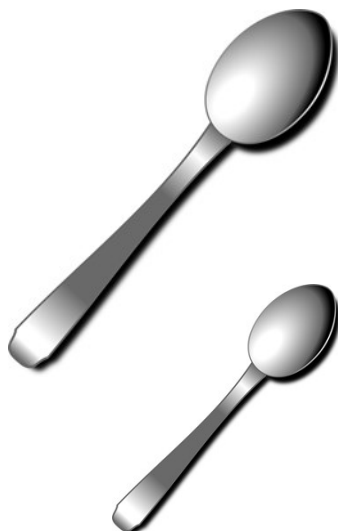
Living with chronic illness is not easy.
Yet I am here and I am still fighting.

Being at war with yourself is hard,
Yet I am still ME and not M.E.

Spoons

Dee Jackman

I'm a spoonie, I say,
Like it makes it okay,
They can't see it's decay,
That I feel everyday.
Some friends stay away,
Others still want to say
That they understand,
They will lend a hand,
But I just want to stand,
On my own two feet,
Without pain on repeat.
I will not admit defeat,
Still arranging to meet,
Let's go for something to eat
Or the cinema for a treat.
I might have to let you down,
Or I'll end up locked down
Because my body's in meltdown,
But the me inside is still around,



'Spoons' and 'spoonie' are terms used by the online chronic illness community to refer to energy and to those who have to conserve their energy like a limited supply of spoons to use for everything throughout the day.

If you look beyond my frown!
Don't give up on me,
Because it's my M.E.,
Not the real me that has changed me.

Dee Jackman is a member of HFwME.

To My Foggy Friends (or To Those Indoors Abed)

Howard Metcalfe

You're in my mind, so come along
With me as I meander away out of town,
In the woods or on the downs.
I point and shoot for you to see from where I stand
The beauty that is all about.
I am so lucky I can point it out.

While still able, this old country boy
Can let you see with me
The same intoxication that the wonders of our landscape
Bring our imagination.
Though the green may look grey in the mist and the rain,
It's still a day of joy.

Not trapped for months in sleep,
I can walk and I can roam over muddy hills
And slimy trails of loam and over fences that might
Trip and rip, or rock-hard tracks set to break my ankles.
I breathe hard the air, the delicious air,
In the rain and the cold and the heat.

Let me take you on my journeys
I'll show you what's to see waiting round the bend,
Through the wood or over the hill.
And oh, soft grass beneath my feet.
There are birds to see flitting through the trees or
Squirrels leaping with ease.
I don't want it to end, for me it is all a treat.

The pic I click is the best I can,
I take it fast while my brain lasts.
Clarity will wither the more that I dither.
Zip lock it forever fresh in digital aspic.
From delusions I am free, I know they are not wonders
But they are the best my addled brain will stand.

You're most welcome my foggy friends
To tag along with me.

Howard Metcalfe is a member of HFwME.

Puzzle It Out

A Gentle M.E. (mind exercise!) Workout

Winter Celebrations Word Search

Winter may be a time of hibernation and darkness but it is also a season filled with celebrations, both secular and religious. How many of the following winter celebrations can you find in the word search below?

Celebrations to Find:

Bodhi Day	Imbolc	Solstice
Candlemas	Krampus Night	Thanksgiving
Christmas	Kwanzaa	Yule
Epiphany	New Year	Valentines Day
Hannukah	Saturnalia	

H K I L A G O P A V B U Z T E
 K R A M P U S N I G H T H R C
 Y S S S J D H G U Z O A I A I
 A Y A A C T D L U U N W M E T
 D R A M T V Y T X K E W B Y S
 S C V D T U V N S C B O O W L
 E M K W I S R G A C D K L E O
 N A W E D H I N G H Z T C N S
 I H L P B V D R A F P S H N A
 T I Y Z I L M O H L P I F K A
 N B U N E P P N B C I L P B Z
 E Z G M Y H A N N U K A H E N
 L G A W L U K O F P O O G K A
 A S P T Y Z L A T P P V M Y W
 V X Z H Y U A E R G U M S K K



Did You Know?

Snippets and Tips for Making Life Easier

Reducing Muscle Pain with Ginger and Cherries

According to *The Food Swap Diet* by Peta Bee:

“Daily **ginger** consumption has been shown to reduce exercise-induced muscle pain by 25%.

Eating about twenty **cherries** a day provides between 12-25mg of anthocyanins, a compound that is a strong antioxidant and also has an anti-inflammatory painkilling effect. With an exceptionally low glycaemic index, cherries are great for stabilising blood sugar levels and keeping hunger at bay. They contain good levels of potassium, which regulates heart function and a cancer-fighting compound called ellagic acid.

Runners who drank **cherry juice** twice a day for five days before a marathon were shown to recover much more quickly and experience less muscle soreness than those who didn’t.”

Words of Wisdom

Life isn’t run by principles but by adjustments.

Margaret Atwood

Those who love you are not fooled by mistakes you have made, or dark images you hold about yourself. They remember your beauty when you feel ugly, your wholeness when you are broken, your innocence when you feel guilty, and your purpose when you are confused.

African Saying

Kitchen Corner

Tempting Recipes That Respect Your Body's Requests

Lentil Bolognese Germaine Hypher

One of my carers was a dedicated healthy eater. This Bolognese is her creation. It is easy to cook in bulk and freeze in portions for future meals when unable to cook.

Ingredients to serve 4

- 8oz/226g whole wheat pasta or spaghetti
 - 1 onion, chopped
 - 1 red pepper, chopped
 - 2 carrots, finely chopped
 - 1-2 garlic cloves, finely diced
 - 1x 14½oz/400g tin of chopped tomatoes
 - 1 mug frozen peas
 - 3oz/85g red split lentils
 - ½ stick celery
 - 3fl.oz/90ml water
 - 1 tbs oil
 - 1 tbs bouillon powder
 - 1 tsp turmeric
 - a few pinches mixed dried herbs
 - grated cheese, to serve
 - a few fresh basil leaves, torn, to serve
1. Sauté the onions for 5 minutes in the oil, over a low-medium heat. Add the carrots, red pepper and celery and continue to sauté for a further 5-10 minutes. Add the lentils and turmeric, stir well and add the tinned tomatoes, mixed herbs and bouillon.
 2. Swill the water around the empty tomato tin to collect any extra tomato juice and pour into the pan.
 3. Bring to the boil, then turn down to a low heat and simmer gently with a lid on for about half an hour, stirring every 10 minutes.
 4. Cook the pasta in a pan of boiling water for 20-25 minutes until al dente.
 5. Ten minutes before the lentil sauce is ready add the garlic and peas and stir well.
 6. Serve with the pasta, fresh basil and grated cheese.



Just For Fun



Amazing Maths Trick

Ask a willing victim to pick a number between 1 and 10 but not to tell you what it is. Tell them to multiply it by 9.

Tell them if the result is a two digit number to add the two digits together. Then get them to subtract 5 from the resulting number.

Beginning with the letter A as 1, B as 2, etc., ask them to count in the alphabet the number they now have in their head. (No matter what number they started with they will always end up with 4, so the letter they will have in their head is D.)

Now ask them to think of a country that begins with their letter but not to tell it to you. (Nearly everyone will pick Denmark.)

Ask them to take the second letter of their country and think of a circus animal that begins with that letter. (Nearly everyone will pick elephant.)

Wait a couple of seconds and say, "but elephants don't live in Denmark!" and watch the amazement on their face.

WORD	REARRANGE THE LETTERS
DORMITORY	DIRTY ROOM
PRESBYTERIAN	BEST IN PRAYER
ASTRONOMER	MOON STARER
DESPERATION	A ROPE ENDS IT
THE EYES	THEY SEE
GEORGE BUSH	HE BUGS GORE
THE MORSE CODE	HERE COME DOTS
SLOT MACHINES	CASH LOST IN ME
ANIMOSITY	IS NO AMITY
ELECTION RESULTS	LIES LET'S RECOUNT
MOTHER IN LAW	WOMAN HITLER
SNOOZE ALARMS	ALAS NO MORE Z'S
A DECIMAL POINT	IM A DOT IN PLACE
THE EARTHQUAKES	THAT QUEER SHAKE
ELEVEN PLUS TWO	TWELVE PLUS ONE