

Serving ME/CFS patients, carers and interested parties in Glamorgan

AGM / Awareness Event 2015

(includes real life recovery stories)

Saturday 16th May

2pm-5pm

Bethel Community Church

Llangranog Rd

Llanishen

Cardiff

CF14 5BL



2-3pm

3-4pm

4-5pm

AGM

Raffle, tea
and cake,
social time
Speakers
giving their
recovery
stories

If you are subscribed to MESiG, we need you for our annual general meeting, to vote in your committee. If you want to be put forward for a role please contact us.

All are welcome to this event, bring friends, family, carers, anyone with an interest. Recovery stories will include both ME and Fibromyalgia. Come and pick up some tips on what helps and maybe share a few of your own.

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MESiG

Christmas Party Review

By Mary Jones

On the first day of December we held our much-awaited Christmas Party at the Bethel Church.

A long table, adorned with red tablecloths and red and green Christmas crackers, was set up. Very soon members and friends began to arrive.

It was good to see the numbers swell to some thirty people, including a new member, despite the inevitable struggle that many sufferers have to endure.

A Bran Tub was placed in the corner of the room containing gift prizes in the form of a "Lucky Dip".



The raffle table had good selection of prizes, donated by members, including a lovely basket of fruit, a basket of fluffy 'bunnies' and a beautiful wooden Christmas plaque, which was hand carved by a member, Steve. There were also tins of biscuits, boxes of chocolates and bottles of wine. Ken also donated a copy of his book, "Where's your Faith? Just Believe", which was also available to purchase.

After the pulling of the Crackers and the donning of the coloured hats we tucked into a magnificent array of assorted sandwiches, wraps, dips, and chicken, together with a container of fruit salad, and various cakes, mostly home-made. All was washed down with a selection of soft drinks, tea and coffee.

Despite holding the party some three weeks before Christmas everyone entered into the spirit of the occasion. It is fair to say that we all seemed to have a good time, enjoying the pleasure of the company that the party provided.

It was a merry Christmas

ME Support In Glamorgan has been chosen to receive free books

May 11th support group meeting 11am-12.30pm.
Please come join us.

World Book Night 2015

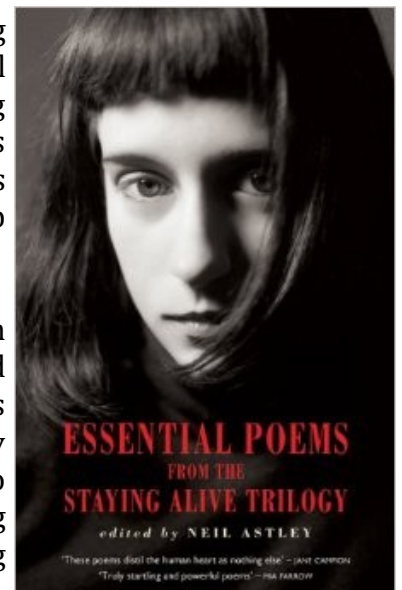
I'm a World Book Night 2015 Volunteer 2015 and I have given out books in 2011, 2012, 2013, 2014. You can read my blog posts on giving out books in 2011, 2013, 2014 [here](#). Also a blog post I wrote for Guardian Cardiff as a World Book Night Giver 2011.

World Book Night started in 2011 and is now run by The Reading Agency. It is an initiative encouraging those who do not read, read very little or who may struggle to read to read more. Each year on April 23rd 25,000 volunteers are chosen to give out one of 25 titles (which have been specifically chosen).

The Book

This year I am choosing to give out Essential Poems from The Staying Alive Trilogy Edited by Neil Astley - Bloodaxe Books. It is a small travel compendium of a number of poems featured in the three books: 'Staying Alive', 'Being Alive' and 'Being Human'. They are a collection of poems throughout the ages from classic to modern, chosen around the subjects of the human condition (ie. loss, grief, transition etc). Intended to help the reader through life.

I specifically chose this book as poetry has been a lifeline for me through a period of physical and mental ill health. I lost the capacity to read novels, stories, longer passages and at my lowest point of illness was unable to read at all. I began reading poetry as a smaller word capacity was more manageable. And over time I also found some poems began to help me to understand my own emotions. I went on to set up a meeting called Incandescent In Cardiff Central Library, where people can bring along their favourite published poems or lyrics to share and discuss.



Why MESIG?

I would like others who may be in similar positions and struggling to read have the opportunity that poetry brought me. So I'm choosing two local organisations to approach, who have helped me and my PA (my mum!) in the past. ME Support in Glamorgan and Hafal.

By Juliette Llewellyn

Dates For Your Diary

Tea In The Park

Monday 10th August 2pm.

We meet in Roath Park café terrace, for a cuppa and chat.
Lake Road East, Cardiff CF23 5PG

All are welcome.

Do come join us



MESiG Support Group Meeting

7th September 11am-12.30pm

Offering Art workshop with Dennis

No art ability needed.

Materials supplied.

Bethel Community Church

Llangranog Road, Llanishen, Cardiff, CF14 5BJ

Come have some therapeutic fun with us.



CLAIRE JONES

JOURNEY

HARP TO SOOTHE THE SOUL



'JOURNEY' THE TOUR: Journey is an album of classical melodies drawn from orchestral repertoire, film scores and the cannon of British folk songs. It is the soundtrack to Claire's own journey to wellness and includes music to relax and unwind, and some to lift the spirits high. Join Claire and her musical guests for an evening of sweeping melodies and virtuosic harp playing as she shares with you the music of her healing

Album OUT NOW

£5.99

Claire's new album, 'Journey' is the music of her very personal journey of recovery from ME Chronic Fatigue Syndrome.

Cardiff Tour Date: Thursday, 18th June

7.30pm, The Gate Arts Centre, Keppoch Street, Cardiff, CF24 3JW

Box Office: 029 20483344 £14 Adults



@clairejones85



Claire Jones

www.clairejones.co.uk

For more information contact MESiG on: 02920762347 mesigwales@gmail.com

POLICY FORUM FOR WALES: PRUDENT HEALTHCARE in WALES: challenges, practicalities and progress.

I attended this forum which was held on February 24th 2015 in a large conference room in the Marriott Hotel, Cardiff. It was attended by many people, heads of departments, Assembly Members, medical personnel, representatives from Groups, from all over Wales. It is a very full morning from 8.30 am until 1 pm. The whole morning, all of the speakers in all of the session and all of the questions from the floor were recorded.

Janet Finch-Saunders AM, Health and Social Care Committee introduced the first session:

The Prudent Approach: Why? And what does that mean?
“Essentially, prudent healthcare is about providing healthcare for all based on Clinical need, and avoiding wasteful care that is of no benefit to anyone.”

It was stated that 2014 was hailed by Mark Drakeford as the year of prudent healthcare, so it is now time to see how the agenda is progressing.

However I think that many of us need to catch up with this view and certainly this was the case for me on this day.

The Welsh Government described prudent healthcare as delivering three objectives:

- 1) Do no harm
- 2) Carry out the minimum appropriate intervention
- 3) Promote equity between professionals and patients

You can look up the Bevan Commission paper on their website and read more about, 'Simple Prudent Healthcare.' The definition given is this: Healthcare which is conceived, managed and delivered in a cautious, safe and wise way that is characterised by forethought, vigilance and careful budgeting which achieves tangible benefits and quality outcomes for patients.

A little earlier in February prior to the forum the final four principles were announced:

- 1) Achieve health and wellbeing with the public, patients and professions as equal partners for co-production
- 2) Care for those with the greatest need first, making the most effective use of all skills and resources
- 3) Do only what is needed and do no harm, no more, no less
- 4) Reduce inappropriate variation using evidence based practices consistently and transparently

I was particularly interested in **co-production**. How often in

the past have we been told what to do by our GP or they have looked shocked if we made a suggestion to them about our health needs, as if we have no right to an opinion as 'they are the doctor'?

Co-production was described by Kamal Asaad, Medical Director, Cwm Taf University Health Board as follows:

“The treatment is genuinely patient centred: Why have you come today? What do you want to achieve? What will make you happy?”

Well, that certainly sounds good and I have noticed this being put into practice at out GP surgery and in other medical situations. We all have a right to an opinion and choice about what to do! From the point of view of people with ME this could prevent unsuitable treatments being push onto patients?

John Griffiths AM was the Chair for the second session of the morning and David Rees AM, Chair for the Health and Social Committee (National Assembly) was the speaker. He discussed the next steps for prudent healthcare, his personal views. At the end of his presentation I asked him a

question (there is a question period after presentations and one is given a microphone so that all may hear). This was what I asked:

“When speaking of co-production, what happens when there is a clash between the GP and the patient, who actually knows best? For example, a GP might see a patient with ME and insist that it is depression or they recognise that ME is a neurological condition but they insist that exercise is the treatment and the cure when the kind of exercise proposed is actually causing that person to get worse. What about 'do no harm'?”

David Rees AM replied to me: “I'm not a clinician so I'm not going to pretend that I am, but I think this question of conversations with a patient is critical because you highlight the concept, what is the patient's view, what is the patient's perspective?...I think that's a conversation that needs to take place so that the 'do no harm' is done in conjunction with a patient. It's critical that this approach is applied to ensure that both the patient and the clinician agree the direction forward. That's the question here and it may come to a point, and I'm not a clinician, as to a clinician makes a decision based upon the health issues of the individual patient but that conversation has to take place first, and

that's what we're trying to say, have that conversation, it is a co-production, it's a joint approach to your health by having a discussion with you and the clinician and I think that's important.”

(Miriam) I then asked: “It has a spin off though with claiming benefits because if a client refuses a particular kind of treatment, they could be refused a benefit because they are not following through with treatment.”

David Rees replied: “Interesting question, I can't answer that question but it's actually the same point which we need to perhaps look at.”

John Griffiths AM added: “It does illustrate how wide ranging it is in terms of addressing health and social care issues, doesn't it because it does bring into play so many different organisations and indeed professionals who are in a position to help or not. So you know it's certainly a point well worth making I think.” The next session of the morning addressed Health and Social integration in practice. One of the speakers, Dr Charlotte Jones, Chair of the General Practitioners Committee Wales, BMA, at the beginning of her presentation said,

“I was quite struck with the lady who talked about ME, and to be perfectly honest, you need to be perfectly honest, you need

to have a relationship with the doctor that you can talk about, and if they suggest something that's not right for you, you can come back. We would like that two way conversation, we're trying to be more centred towards the patients, and not dictate to them.

But sometimes, we are constrained by the resources we have available to help...”

The whole morning was revealing but it was hard going to listen to so many speakers one after the other. It would be too much to name everyone and what they said but if you are interested in knowing more, I could share it with you. These meetings are held at regular intervals and it is essential to know what is happening health-wise in Wales.

It is also good to be there to make other people aware of ME and the problems that are being experienced.

Written by Miriam Wood, Political Liaison Officer MESiG

The Petition

As you may know, MESIG submitted a petition to the Welsh Assembly Government as below: -

MYALGIC ENCEPHALOMYELITIS (M. E), CHRONIC FATIGUE SYNDROME, FIBROMYALGIA

WE, the undersigned, wish to register our aspiration to have a dedicated consultant/ clinic and medical support team for the above named illnesses. Currently there are no such facilities despite the fact that M.E affects many people living in the South Wales area.

WE believe there is just cause to have a recognised clinic & staff and accordingly we request that this petition be treated as an official voice of ME sufferers, their families, carers and interested parties.

Having been submitted, using hand signed documents and the on-line facility afforded to us through the Welsh Assembly Government, the Petitions Committee considered and accepted it to go forward.

Meanwhile the WAG had commissioned a Task and Finish Group to consider the implications of the issues associated with ME/CFS/FM to look for a way forward. The T & F G produced a report to which, when we had sight of it, MESIG responded, an extract of which is below.

M.E. is defined by the World Health Organisation as a neurological condition, so it's encouraging to see that the Neurological Conditions Delivery Plan is referred to in the report (specifically in Recommendation 4) as forming the basis for developing effective local pathways for children and adults with ME/CFS and Fibromyalgia. It is of concern however that despite ME being defined as a neurological condition, the Neurologists that we have come across say that ME is not a neurological condition. Following from this, it's important that the clinical leads for ME/CFS and Fibromyalgia within each Local Health Board have experience of treating patients with neurological conditions. Can you tell us why so many psychologists are members of the Task and Finish group?

The urgent need for timely and appropriate healthcare for people with ME/CFS and Fibromyalgia cannot be overstated, particularly those who are most severely affected and house- and/or bed-bound.

The appropriate committee discussed the petition, albeit for a very short period of time.

It was clear that the committee was not happy with the way that the Area Health Boards were so slow in responding in relation to the way forward.

The current situation appears to be as follows in an extract of an e-mail received today (16th March 2015):

As discussed, here is a summary of the last action agreed by the Committee:

The Committee considered correspondence on the petition at the meeting on 20 January and agreed to write to the Minister:

Drawing his attention to the petitioners' further comments in particular their concerns that these conditions are viewed as psychological rather than neurological conditions; and
· seeking further information on progress in establishing the All-Wales Implementation Group.
As soon a response from the Minister is received I will of course notify you. We would expect to receive a response from the Minister in readiness for the next Committee meeting on 28 April.

As and when more information is received from the committee clerks we will be able to update.

By Mary and Dennis Jones

Chair Report

April 2014-April 2015

26th April 2014

AGM 3.30pm-5.30pm. Mackintosh Centre, Keppoch Street, Roath.

6th May 2014

Dee and Miriam representing MESiG were interviewed by Cardiff Radio. A great opportunity to speak about the M.E film being shown in Penarth cinema and the stand in Heath hospital.

7th May 2014

MESiG have a teleconference with Clare and Sonia from Action For ME in order to unite in moving forward.

12th May 2014

MESiG present ME film 'Voices From The Shadows' in Penarth cinema. 2pm, in conjunction with ME awareness week. Thank you to that special person who made this possible. You know who you are.

13th May 2014

M.E stand at the Heath hospital 9am-5.30pm. Raising awareness and collecting signatures for the petition for services for people with M.E/ CFS and Fibromyalgia.

21st June 2014

Llanishen fun day. MESiG had a stall raising awareness about ME and funds of £230. Raffle, candy floss, name the bear, lucky dip and stocks were offered.

10th August 2014

Annual meet up for Tea In The Park. Roath Park Cafe.

16th September 2014

Presentation of Petition to Welsh Assembly.

28th September 2014

Funds for MESiG raised by Nick Tatham who took part in 'Survival of the fittest'. A 12k run with obstacles held in Cardiff Bay. Over £1000 raised. Christmas Party Bethel Church 2-4.30pm.

1st December 2014

March and April 2015

Support group meetings held in Bethel Community Church not Community shop.

23rd April 2015

Petition meeting in Welsh Assembly.

16th May 2015

AGM/Awareness Event 2-5pm, Bethel Church. Stories of recovery.

Film about Lyme Disease

Under Our Skin:

"A chilling tale of microbes, medicine and money, this Oscar shortlisted film has changed the landscape of the Lyme epidemic, bringing unprecedented awareness in an engaging and accessible way. The definitive record of the Lyme controversy, UNDER OUR SKIN exposes a hidden story of medical and scientific malfeasance and neglect. As official case numbers explode and hundreds of thousands of people around the world go undiagnosed or misdiagnosed, the film is as relevant and timely as ever."



3-Minute Movie trailer :

<http://underourskin.com>

98-Minute movie :

<http://hulu.com/#!/watch/268761>

The Sequel :

www.underourskin.com/sequel

My life with NON HIV AIDS

(incl: federal testimony) : <http://maxresistance.com/proof-new-designer-aids>





Treating Chronic Fatigue Syndrome and Fibromyalgia: A Free Online Self-Study Course

Having CFS or fibromyalgia can be discouraging, but you can take charge one step at a time. This site, which is a free self-study course, will guide you step by step through the process of creating an individualized treatment plan.

More than 80% of people improve when treated with the approach you'll find here, which combines the best of medicine with self-management.

Your teachers are a health educator and a physician. Dr. Campbell created self-help courses on CFS and FM that have been taken by thousands of people since 1998. Dr. Lapp has focused for more than 25 years on treating people with these conditions

Getting Started

If the idea of creating a plan feels overwhelming, relax. We'll help you take it one step at a time. To get started, check out the [How to Use This Site](#) page. It will show you how to begin.



Bruce Campbell, Ph.D.
Creator
CFIDS & FM Self-Help Program
Palo Alto, CA

Success Story

Pacing and Exercise

For many years, I didn't exercise regularly because I couldn't figure out how to exercise in a way that didn't make my symptoms worse. Then I realized that it might be possible to exercise successfully if I applied the idea of pacing in this part of my life, just as I had elsewhere.



Charles Lapp, M.D.
Director
Hunter-Hopkins Center
Charlotte, NC

For more information visit— <http://www.treatcfsfm.org/>

Stop Press

Good news:

One of our members is just settling into her new home. She had been renting privately but was overjoyed when she was offered a one bedroom house in a quiet area. It has an adapted bathroom and a stair lift.

“ I thought that I'd be on the waiting list for a long time but it was only about two years,” she says.

This happened because she had registered with Accessible Housing.

“I encourage anyone to register with them, as on the Council Housing list, even with extra medical points, it could take 7 to 10 years to be offered a home.”

If you want to register you now have to call your local HUB for an appointment and the registration is done through them.

It was a massive struggle for her to make the move and caused her M.E. to flare up, so it was a very stressful time. Fortunately some work was done in the house before she moved in, as it had not been decorated for a long time. Now it is worth all the exhaustion and stress and she is beginning to settle down.

Not such good news:

One member who has been ill for 4 years is still waiting to get a diagnosis! Chris was able to go with her to visit her GP who stated that she is unable to diagnosis M.E. even though other causes have been eliminated by tests. Neither can the other GPs in the Surgery give a diagnosis and she cannot be referred out of the area. But out of this there is to be a discussion at Assembly level as the ability to diagnose M.E. is essential and the guidelines for doing so are very clear.

SOS:

We received a plea from a woman in West Wales who is suffering badly and cannot get some of the basics required or the understanding that she needs to live. She obviously is too far away for us to help her on a regular basis but Chris and Ken 'just happened' to be going to West Wales for a few days break and were able to call and visit her and her husband., plans are underway to get some support locally

Another woman who is in great difficulty but lives just outside our area has been put in touch with us by an Advocate from the 25% M.E. Group. We are talking to her regularly and seeing what we can do to support her.

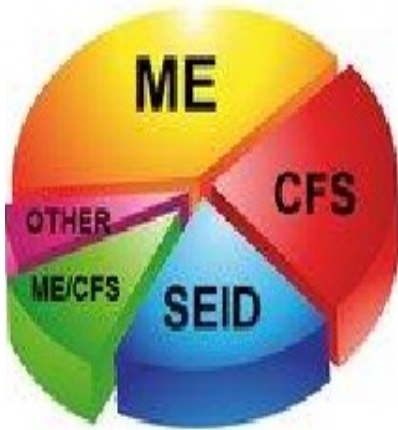
Very good news:

A Cardiff GP contacted MESiG to ask if he may signpost M.E. patients to us, as he has read our website and is impressed. The answer was Yes please! We need more GPs like him!

By Miriam Wood

SURVEY RESULTS:

What Name Would YOU Choose for CFS?



In September 2013, the IOM (Institute Of Medicine) was contracted by HHS (Health and Human Services) to devise a new definition for chronic fatigue syndrome (CFS), the current CDC definition being considered too broad. It was also charged with providing a new name at its discretion. The IOM made its recommendations on Tuesday, February 10, 2015 in a report entitled, "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness." One of the recommendations of the report was to eliminate CFS and to replace it, as well as myalgic encephalomyelitis, with "systemic exertion intolerance disease" (SEID).

On February 26, 2015, ProHealth conducted a survey on the proposed new name for ME/CFS

The survey consisted of three questions:

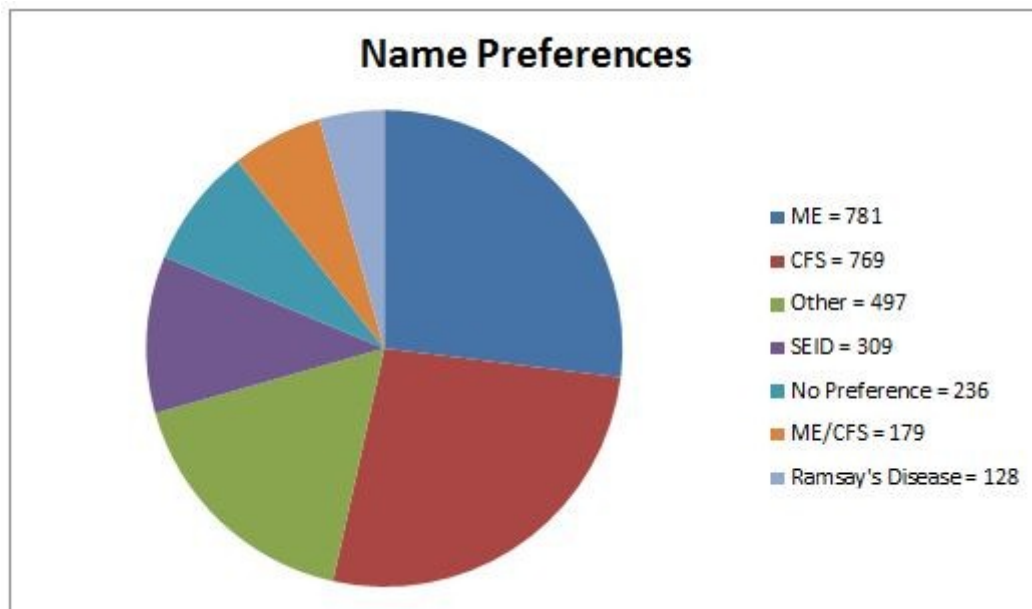
- 1) Do you have CFS or ME?
- 2) Do you think CFS should be replaced by a new name?
- 3) Please choose which name you would prefer.

(Respondents were given a choice of myalgic encephalomyelitis, ME/CFS, Nightingale's Disease, Ramsay's Disease, SEID, Cheney Peterson Disease, Incline Village Disease, and No Preference. In addition, respondents could make suggestions for additional names, and make comments.)

A total of 3059 people filled out the survey, making it the largest survey to date on the proposed name change. Of those, 2690 respondents reported having either ME or CFS. Of those who did not have either diagnosis, most had a family member with the disease, or had been diagnosed with FM, as this was the condition most frequently mentioned in the comments.

The majority of respondents (75%) thought that CFS needed to be replaced. The reasons given were primarily that the name was trivializing, and did not capture the scope or seriousness of the illness. The 25% of respondents who did not agree that a new name was needed gave familiarity, ease of pronunciation, and accuracy as reasons to keep CFS.

The name which garnered the most support was myalgic encephalomyelitis (781 votes). The reasons given were historical continuity, accuracy, and medical weight. SEID got 309 votes. The reasons given were accuracy, and inevitability ("It's too late now to do anything about it.") 179 people wanted to keep the current name ME/CFS for reasons of accuracy and continuity. Aside from Ramsay's Disease, the remaining names garnered very few votes. Those who commented on the choice of the remaining names mentioned that they did not know who Cheney or Peterson were (or Ramsay) and that they had no awareness of the significance of Incline Village or how Nightingale might be associated with the illness.



Comments from Respondents

Respondents had a great deal to say about the name change. Below are just a few comments listed. The survey garnered 146 pages of additional comments, the majority of which were critical of both CFS and SEID as appropriate names for the disease. Some of the critical comments of the proposed name SEID are as follows:

"People are going to make jokes about the name systemic exertion intolerance disease."

"NOT SEID, which is an even worse name than CFS." (7 people made a similar statement.)

"Not SEID. Too much negative stigma." (31 people made a similar statement.)

"Until they are able to specify exactly what disease people are suffering from, it would be prudent to stick with ME which most people are familiar with." (12 people made a similar statement.)

"CFS is an appalling name, as is SEID. It is associated with being lazy and nothing could be more untrue. Stick with ME - we all know what this is and can easily identify with the name." (13 people made a similar statement.)

It is very clear from the 167 pages of comments that patients with this illness have strong concerns, not just about the name change, but about the lack of funding, the lack of recognition, and the lack of patient care. Regardless of the suitability, or unsuitability, of SEID, the problems people with ME/CFS encounter in the medical world are profound, and cannot be fixed with a simple change of name.

Copies of this report as well as full results of the survey were sent to the IOM, HHS Secretary Burwell, and ORWH Deputy Director Susan Maier.

For the full article visit

<http://www.prohealth.com/ME-CFS/library/showArticle.cfm?libid=19821&B1=>



The Fibromyalgia Exercise & Diet Guide by David Jenkin

This Guide covers:

- A Review of the latest research
- The Warm up
- Joint Mobilisation
- Mobilisation Exercises
- Low Intensity Pulse-raiser
- Stretching
- Home Based Chair Exercises
- Standing Exercises using a Chair or Support
- Low Impact Aerobic Exercises
- Strength Training Exercises
- Aqua –Exercise
- Managing Flare Ups
- Exercise Pacing
- Diet and Nutrition Plan
- SMART Goals
- Lifestyle Changes
- Posture
- Medication
- Pain
- Exercise Plan
- Symptom Diary
- It's NOT "all in your head"
- "The Basics of Managing Fibromyalgia" by Dr Jacobi

***BRAND NEW 2015 ***

The 85 page guide is designed to teach people how to be active managers of their health in relation to living with Fibromyalgia.

Only £14.95 including post and packing to a UK postcode

There is increasing evidence that a regular exercise routine is essential for all fibromyalgia syndrome patients. This is easier said than done because increased pain and fatigue caused by repetitive exertion makes regular exercise quite difficult. However, those patients who do get into an exercise regimen experience worthwhile improvement and are reluctant to give up.

The guide is designed to teach people how to be active managers of their health in relation to living with Fibromyalgia.

Please note: this article is for Fibromyalgia not M.E.

For more details visit:

<http://www.ukfibromyalgia.com/treatments/self-help-exercise-guide-fm.html>

Health Rising:

Looking for Answers to Chronic Fatigue Syndrome and Fibromyalgia



Could A Mitochondrial Enhancer Replace Cymbalta in Fibromyalgia?

By [Cort Johnson](#) on April 11, 2015

How a Mitochondrial Booster Became an Antidepressant

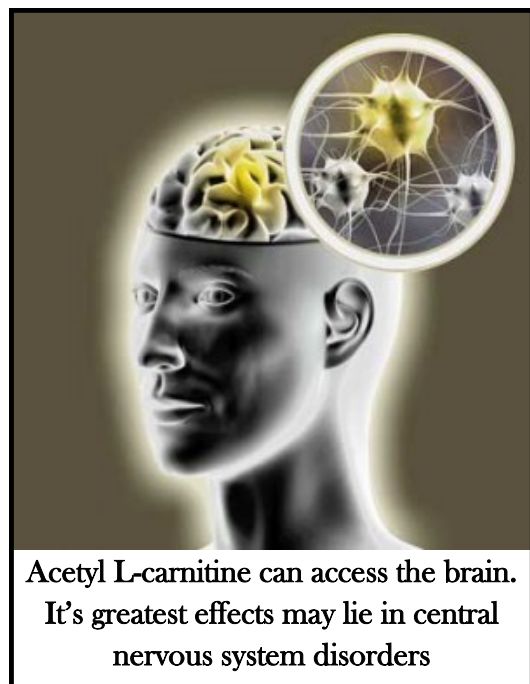
Acetyl0 L-carnitine (ALCAR) is best known as an energy supplement and mitochondrial booster but folks in this fibromyalgia clinical trial were looking for more than increased energy; they were looking for relief from pain and depression as well. They pinned ALCAR not as an energy booster per se, but as a central nervous system protectant – and they had good reason to do so.

Read more: [Could A Mitochondrial Enhancer Replace Cymbalta in Fibromyalgia?](#)

<http://www.cortjohnson.org/blog/2015/04/11/mitochondrial-enhancer-cymbalta-fibromyalgia/>

Acetyl L-carnitine

Acetyl- L-carnitine's (ALCAR) transport of the important metabolic factor Acetyl CoA into the mitochondria increases energy production. Similar in structure to acetylcholine, it also stimulates acetylcholine production and enhances cellular membrane health. acetyl L-carnitine depression Acetyl L-carnitine can access the brain. It's greatest effects may lie in central nervous system disorders Central Nervous System: It's where it does all this that is key. By enhancing energy stores and maintaining membrane fluidity in neurons it may reduce neuronal death. By reducing glutamate levels and oxidative stress in the brain it appears to reduce central nervous system excitotoxicity. Either way it appears to have neuroprotective factors. It's been and is being studied in a variety of nervous system disorders. Larger clinical trials are needed, but a 2014 review suggested that acetyl-L-carnitine may be able to alleviate depression. Acetyl-L-carnitine reduced hyperactivity and improved social functioning in two trials of ADHD patients with Fragile X Syndrome.



Acetyl L-carnitine can access the brain.
It's greatest effects may lie in central
nervous system disorders

A trial featuring hepatitis patients taking interferon may have the most relevance for chronic fatigue syndrome (ME/CFS). Acetyl-L-carnitine significantly improved both biological parameters (including viremia), as well as many physical factors (physical and mental fatigue, pain, physical functioning and vitality). Miller's basal ganglia studies suggest ME/CFS patients and hepatitis patients receiving interferon have similar types of brain dysfunction. They suggest inflammation/oxidative stress induced basal ganglia damage may be causing fatigue in both groups.

* Unrewarding Reward: The Basal Ganglia, Inflammation and Fatigue In Chronic Fatigue Syndrome
asal Ganglia

*Dopamine, the Basal Ganglia and Chronic Fatigue Syndrome #II – Treatments

Peripheral Nervous System

Acetyl-L-carnitine may also improve peripheral nerve functioning – a possibly important factor given the high incidence of small fiber neuropathy in FM (approx. 40%). Six months of ALC supplementation (1,500 mgs/2 x's daily) significantly increased sensory nerve density and reduced neuropathic pain in HIV patients with retroviral drug-induced nerve damage. A recent meta-analysis suggests acetyl-L-carnitine has moderate pain-reducing effects in peripheral neuropathy.

Results

This Italian study randomized 65 female FM patients to either duloxetine (Cymbalta), an FDA-approved treatment for fibromyalgia, or 500 mgs. of acetyl-L-carnitine (three times a day) for three months. Fibromyalgia impact, pain and mood symptoms were assessed at several points during the trial. acetyl l carnitine improves functioning in fibromyalgia Acetyl L-carnitine as as effective as Cymbalta in improving depression, well-being and physical functioning Join Health Rising's ME/CFS, FM and Chronic Pain Forums! ForumsFind good doctors, check out recovery stories, review treatments and get help in the Health Rising ME/CFS, FM and Chronic Pain Forums here Both treatments produced significant improvements in depression, overall well-being, and physical functioning. Duloxetine improved pain. In contrast to earlier findings in FM and other disorders, ALCAR did not. Anxiety was not significantly improved in either group. Serious side-effects appeared to be significantly reduced in the ALCAR group compared to the Cymbalta group. (Side-effects prompted almost twenty-five percent of FM patients to drop out of one study.)



Reduced Synergy = Reduced Results?

No studies suggest acetyl L-carnitine has other than moderate effects in disease. Moderate effects in many chronic diseases, however, can present a significant step forward.

Studies may also be under-estimating acetyl L-carnitine's potential effects by using it in isolation.. Jon Kaiser of the aptly named Synergy trial asserts acetyl L-carnitine is much more effective when taken with alpha lipoic acid (ALA) and n-acetylcysteine (NAC). That formulation was effective in boosting the immune functioning of HIV/AIDS patients, but was not as successful in people with chronic fatigue syndrome.

Kaiser found that adding other nutrients plus a stimulant (either caffeine or methylphenidate) was much more effective in ME/CFS. Acetyl-L-carnitine in combination with other nutrients (folate, alpha-tocopherol, B12, S-adenosyl methionine, N-acetyl cysteine) improved some cognitive functions in an Alzheimer's trial.

Wrap Up

Acetyl-L-carnitine's ability to go toe to toe with an FDA approved antidepressant in the areas of mood, well-being and physical functioning in FM was impressive. Its inability to move the needle on pain was a bit surprising given study evidence it can do so in peripheral neuropathy. No studies to my knowledge, however, have determined how much of a contribution the small fiber neuropathy in FM makes to pain levels in that disorder.

It should be noted, though, that Cymbalta is not particularly effective. The number of FM patients needed to treat in order for one to have a fifty percent improvement in pain is seven (@ 120 mgs/day).

The study may also have underestimated the effects ALCAR can have when given in conjunction with other nutrients. Kaiser, for instance, asserts ALCAR is much more effective when used with alpha lipoic acid and NAC. Acetyl L-carnitine - nervous system protectant Acetyl L-carnitine may be able to improve central and peripheral nervous system functioning



Acetyl L-carnitine may be able to improve central and peripheral nervous system functioning

The lack of a placebo control group made it impossible to tease out placebo effects from treatment effects. Numerous studies suggest ALCAR's ability to increase energy reserves in neurons and maintain cell membrane health and reduce oxidative stress could have positive effects on both central nervous system and peripheral nervous system functioning.

Can a mitochondrial enhancer like ALCAR replace an antidepressant and pain reliever like Cymbalta? The evidence at this point is too sparse to say so. ALCAR has not received the large-scale trials Cymbalta has in fibromyalgia. Given it's few side effects and ease of purchase, however, this study and others suggest it may be worth a shot in pain, neurological and mood disorders.

Inquiry of the Day: Were you ever prescribed antidepressants for ME/CFS or fibromyalgia and, if so, how did it go. Take the poll on Health Rising's Forums and tell us here.

Share your experience: with Cymbalta or acetyl L-carnitine in the Review section of Health Rising's new ME/CFS, FM and Chronic Pain Forums.

For more information visit—

<http://www.cortjohnson.org/blog/2015/04/11/mitochondrial-enhancer-cymbalta-fibromyalgia/>

Good News About Benefits

Most people find the thought of applying for Benefits a daunting subject. First of all, when you start thinking of applying, other people are very quick to be negative and tell you stories about how impossible it is and advise you that it's not worthwhile trying. Do not fear, it is possible and it is worthwhile!

Just take the first step and make the phone call to apply for the form. They will ask you certain basic questions but if you are asked more, about your health or disability, you could always say that you can't talk for long on the phone, especially if you have problems listening and thinking quickly.

Once the form arrives, it may look daunting. If you live with someone who understands your needs and is adept at filling in forms it can be easier but we have found that there are many people who do not have a supportive person who understands and is able to help.

The good news is that MESiG has had repeated success in assisting members with these claims. For example, some time back we were contacted by an MP's office to support a person due to go for an ESA medical. We were able to provide an escort and the benefit was awarded. Later the same person was encouraged to apply for PIP and we helped with the initial phone call to order the form. We then worked together to fill in the form, one or two questions at a time, as more than that was far too stressful and exhausting. A few weeks later we were delighted to hear that this member had been awarded the maximum benefit. Shortly afterwards we heard that another PIP application, for a member outside Cardiff, had also been successful. Both of these awards were made without face-to-face assessments.

Some members have been asked to change from DLA to PIP. A lot of work went into these forms to word them correctly. Face-to-face assessments were held at home but one was in Cardiff's Capita office. Each of these was successful, although one was referred back for reconsideration before the full benefit was finally awarded.

Capita's office is not very easy to access with only a few disabled bays in a side road, that are usually full. There is a ramp from the street into the reception area, where one waits until called to go by lift to the 5th floor. That office reception is tasteful and quiet. The interview room we went into was small and there was no easy chair or couch, which I thought would have been beneficial for a disabled person to rest on during the assessment. We just went through all the questions again, one by one. It is essential to photocopy the forms before sending them in, a) in case they get lost in the post b) to look back on for future applications c) to read through before and during the assessment, as a reminder.

It is essential to fill all forms in as fully and accurately as possible. It is very easy to say things that you are sure are true but are not factual. For example, you know that you can cook a meal so you tick the Yes box. But is that really true? For example: When did you actually prepare and cook a meal? Two weeks ago? You started to get a meal ready but you had to lie down. You put something in a pan but fell asleep and woke up when the smoke alarm went off? Or you started to cut up some vegetables but chopped your finger and dropped a dish onto the floor and it smashed? But you KNOW that you can cook...? But can you do it as often as needed, safely and in a reasonable time? No, of course not! So do not allow yourself to say that you can do things that you cannot actually do.

If you want help to claim a benefit we may be able to assist you by helping you to think through the answers carefully and honestly. So please do not be put off by others, or by thinking that you could be considered a fraud. Your health needs are why these benefits are available. Of course you can think of someone who is worse off than you are, even when you are feeling very unwell. Yes, though you have your arms and legs and sometimes you feel 'marginally better', be honest and admit it, life used to be very different before this illness came your way.

By Miriam Wood

Holistic Management and Recovery from M.E. / CFS

Dr Claire J Bowen



UNIQUE PERCEPTIONS

Last week I drove a total of 550 miles - around the country, visiting clients. Yesterday I spent a couple of hours in town with my two stepchildren, shopping for various teenage 'essentials' and going to the bank. I also completed a full week's family shop in a busy supermarket. Today we are entertaining my parents for lunch and dinner - my wonderful husband is cooking, though that's just because he's more of a competent chef than I am! Oh - and I'm currently thirty-two weeks pregnant expecting my first, longed-for child.

If you'd told me just a few years ago what my life would be like today, I wouldn't have believed you.

If you'd told me ten years ago that my life now would be like this, I would have laughed at you - except I wouldn't - because I just didn't have the energy for laughing - it would have been a weak smile instead...

Just over ten years ago I was in constant pain and barely had enough energy to roll over in my duvet and pillow-filled bed by myself. I was blessed to have amazing parents, who, despite me leaving home several years before, took me back in and took care of all my personal care needs - including obtaining a commode and all

those 'enabling' gadgets that are so useful yet most of us so hate having to use.

But let me start at the beginning of 'my story'. Until I was about five I was a pretty normal reasonably healthy little girl, normal life, happy family etc. When I was five I had a couple of nasty infections - no hospital, but lots of antibiotics and things that definitely left their mark.

When I was eight I had sinusitis and a flu-type illness. The symptoms of this changed and worsened and led to me having practically a whole year off school, spending much of that year in bed, often unable to walk due to the pain and fatigue and muscle weakness. Not unusually in the 1980s, I was labeled as having 'school-phobia' and 'depression' - even ending up in hospital for a week or 2 when things were at their worst. After about twelve months, when the hospital were discharging me from outpatients since they said there was nothing else they could do, one junior doctor diagnosed me with M.E. My first 'label' in this area.

As time went on, we learnt about pacing and avoided foods that seemed to make things worse and I gradually improved - a natural remission state I believe now. My sensitivity and stamina

remained pretty low, but like many individuals with this condition, my natural instinct was determination to succeed and carry on despite whatever setbacks, so I continued my childhood and teenage years struggling somewhat, but 'managing'.

To cut a long and very up-and-down story short, when I was sixteen I contracted another flu-type illness which transformed into severe pains of different kinds throughout my body, especially in my hands and legs. Coupled with the fatigue, brain fog and lack of balance etc, I was given a diagnosis of Fibromyalgia and told it was unlikely to improve - and that I should 'choose a stress-free career'...

I'm obviously an introverted rebel at heart, since this didn't deter me from applying to Medical School for a career in that 'so stress free' field of medicine! The following years were quite challenging, with my health pretty up and down, but I did manage to complete my Medical training and pass my final exams (well, just - I was pretty unwell during finals and a couple of friends literally had to half-carry me to the exam hall).

After a year's working as a Junior Doctor in Nottingham, I was given a place on a GP training scheme in

Lincolnshire. I already knew that I wanted to treat my patients as holistically as possible, so General Practice seemed the obvious choice.

In June 2002, I woke up one day aching all over, with a stiff neck, swollen glands and a fever. This was the start of my worst period of ME / CFS. After seven days in bed with a fever and 'proper flu' symptoms, the fever subsided and the myriad of symptoms we have all come to know (yet definitely not love!) suddenly returned with a vengeance. The next couple of years are a bit of a blur. At my worst, I was completely bedbound, barely able to speak or communicate, with the constant diversity of pain throughout my body, almost welcoming the severe brain fog that stopped all the negative and often suicidal thoughts from chasing round my mind. After about 6 months of getting so severely ill, I remember thinking that my family was the only good thing left in my life. I'm eternally grateful for their love and support, since over the course of a few months I felt I'd lost everything else - my long term relationship (he just couldn't cope with me being ill), my job, my career, my flat, all my savings, as well as many of my friends - who were mostly medics who didn't really believe or certainly couldn't understand about this weird condition I had...

As is usually the case, I had bad days and better days - bad patches and better patches.

So now to the most significant part of my story - how did I go from being so completely

wiped out and functioning at minimum levels, to leading the life I'm enjoying and so grateful for today?

Like many people with this condition, I'd tried so many things by this point - various drugs - whose side effects I just couldn't deal with, even at the lowest doses, Reflexology, Homeopathy, CBT, Chinese Herbs - to name but a few! Occasionally I received a little symptomatic relief, though often these therapies and treatments just precipitated what I now recognise as a 'healing reaction' or 'detox reaction', which made me feel even worse!

So for me the first major step came with a strong feeling that I wasn't getting enough oxygen into my body! *(I've since found there are numerous studies demonstrating low oxygen levels in individuals with ME / CFS - and others showing how well symptoms can improve by improving said oxygen levels. Please email me if you'd like a copy of these references).*

This overwhelming sense of oxygen being 'key to kick starting my recovery', led me to obtain an Activated Oxygen device (different from traditional oxygen therapies, really preferable in ME / CFS, since it avoids oxygen toxicity and worsening of the condition), which helped improve the oxygen levels within my body, whilst aiding detox and having a strong 'anti-oxidant' effect within my cells. The effects of this were huge (not a miracle cure, though it certainly started to turn my life around!) and included me feeling as if I was



starting to get my brain back again (I felt my IQ had been halved upon becoming ill). This, coupled with increased energy levels, meant I was able to start researching why oxygen might be so important in ME / CFS - and what else was relevant. Little by little I started to piece together information from others' research and my own intuition and experience that led me to develop a 'model' of the cause and development of ME / CFS - and subsequently a model for recovery - through addressing the relevant causative aspects in an accessible, comprehensive way.

This is not meant to be a scientific paper, though if you'd like a copy of my 'Aetiological Model' medical paper, please email me.

The basis of the model, which easily draws together most, if not all of the 'theories of causation', I've come across so far, is 'accelerated oxidative injury' - put simply, ME / CFS is caused by the damage to cells and organs throughout the body caused by 'free radicals' - unstable particles that can be created by normal bodily processes as well as through the taking in of 'toxins' from the outside world.

Combining certain genetic tendencies (including a certain type of personality which in general the world benefits from, though the individual often suffers for their endeavors and conscientiousness...) pre-disease developments, trigger events and perpetuating circumstances, the model I work with can explain most, if not all the specific and systemic symptomatic experiences of ME / CFS.

More significantly, following on from understanding the underlying processes of the condition, by embracing the need to address each causative aspect and effect in turn, the body can be guided to begin to rebalance and heal itself - a kind of re-programming or 'upgrade' at a cellular level.

I'm very aware that every person's experience of ME / CFS is individual and unique. Yet there are so many commonalities within the illness experience and also in

the recovery process. The Holistic (meaning 'whole person', whole life, whole lifestyle - not just physical support) Recovery Programme I have put together (which helped me recover my own health and which I now work through with my clients) is not a 'one size fits all' management plan - it needs to be specifically tailored to the individual, to suit their own needs, preferences, life experiences and lifestyle. However, I believe that for every individual there are five areas which need addressing by appropriate means in order to comprehensively and sustainably improve health and quality of life. These key areas are: Detoxification, Oxygenation, Hydration, Nutrition and Protection. Protection is perhaps the 'broadest' area to be covered, since it includes physical, environmental, mental and emotional protection - and in some ways can often be the most challenging aspect to

address.

The experience of ME / CFS can be extremely challenging (understatement!) isolating, confusing and demoralising - often for the whole family and contact circle of an individual with a condition. With appropriate support and interventions though, there can be light at the end of the tunnel and the creation of the life you truly want to be living. May you find the right path for you to experience wellness and ease again.

For more information, your free guide to ME / CFS Holistic Recovery and a free 15 minute mini telephone consultation, please contact me via email: drclaire@uniqueperceptions.co.uk or on 01299-833-972.

Dr Claire Bowen now works as a Holistic doctor, using established natural medicine principles and cutting edge healthcare technologies to support individuals who are experiencing chronic illness to fulfill their potential for optimum health and well-being. She is based in Worcestershire and runs Unique Perceptions Therapy Practice and Airnergy Rental with her Psychotherapist husband Simon Rowe. www.uniqueperceptions.co.uk

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Dr Claire Bowen is a former GP, turned Holistic Practitioner who, having recovered herself from severe and long-standing M.E. / CFS, now uses a range of tools & techniques in Natural Healthcare to work in partnership with you and in synergy with your body (avoiding side-effects & complications) to explore the greatest level of health and wellbeing available to you. By combining her medical knowledge with alternative & complementary approaches, she offers a warm, compassionate & powerful Recovery Support Plan tailor-made for you.



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Treatment and Management of M.E. / CFS



There is, as yet, no universally successful treatment or cure for ME/CFS. At this stage, the major focus is on managing the illness.

There is some evidence that the earlier a positive diagnosis of ME/CFS is made and the earlier a management regime is adopted the greater the chance of improvement.

Establishing food malabsorptions, food intolerances and gut dysbiosis can be very helpful in managing symptoms.

Individualised management plans

The widely recommended approach to the treatment of ME/CFS is for a flexible, individualised illness management plan to be drawn up in relation to the person's particular symptoms, total illness burden, illness history and other personal circumstances.

This approach recognises that everyone is different, that symptoms fluctuate and the person with ME/CFS is the one who knows best their symptoms and activity capacity at any one time.

The need for the treating practitioner to recognise the biological pathophysiology of the illness, to respect the illness experience of the individual and for the person with ME/CFS to have autonomy concerning the complexity and pacing of activities has been emphasised. (1) (18)

It is important that the treating medical practitioner and person with ME/CFS work together in constructing a management plan.

Symptom and activity management and various self-help strategies can alleviate some symptoms and reduce the severity of post-exertional malaise, leading to some improvement in health and quality of life over time.

"The primary therapeutic goal of lifestyle adjustment - to determine that with which the patient can cope without aggravating her/his symptoms - remains of paramount importance, and should not be neglected in the search for remedies." (Carruthers et al, 2003)

There are no scientifically proven cures for everyone with ME/CFS. Any commercially available product or treatment promoted as a cure for ME/CFS should be treated with caution.

Pacing

The challenge of any chronic disease, including ME/CFS is to learn how to live within the limitations of that disease.

The challenge with ME/CFS is learning to live within an extremely delicate balance between energy supply and energy expenditure, and when this is out of balance symptoms will flare.

Pacing is a key strategy to keep ME/CFS symptoms manageable and to lead a consistent life

style. Pacing will assist a person to move towards a higher level of wellness. The alternative approach is the 'push' and 'crash' cycle, which is unhelpful, frustrating and can lead to further complications.

There is a tendency for people with ME/CFS to 'push' when they are feeling improved and to continue activities until symptoms worsen, by which time it is too late to prevent

post-exertional malaise and a 'crash' from which recovery can be prolonged.

The view of many people with ME/CFS (and many experienced ME/CFS practitioners) is that, in order to keep going in the long term, it is important to pace oneself on a daily basis. This involves scheduling all activities with thought and flexibility, adopting energy-conserving practices, mixing activity with

breaks and stopping activity (mental and physical) before serious symptom exacerbation occurs. There are usually signs that may be different from individual to individual, that indicate that one's limit is approaching. A person with ME/CFS learns these signs through the experience of living with ME/CFS.

A variation on pacing is 'pacing and switching', which involves changing activities to avoid tiring specific muscles. For example, this might include switching from reading before the eye muscles tire to talking and then switching back later (9).

Pacing recognises that even minimal physical or mental exertion may exacerbate symptoms; it accepts that the symptoms may reflect on-going disease; it accommodates the fluctuating nature of ME/CFS and allows maximum activity without worsening the illness.

Pacing is probably the most universally practised and successful ME/CFS coping mechanism. Pacing is not a cure but anecdotal evidence is that many people who adhere to pacing slowly improve.

There is also research and survey evidence that supports the effectiveness of pacing. For example, in a survey of CFIDS Association of America members, of the 820 who responded, 71% considered pacing helpful and none reported adverse affects (10). In a survey carried by Action for ME (UK) 89% of 2338 people with ME found pacing helpful and only 2% thought it made them worse (12). Research evidence supporting the effectiveness of pacing is summarised by psychologist Dr Ellen Goudsmit in (9).

Dr Ellen Goudsmit was the first person to describe pacing and has written a number of papers about it, such as (9) and an

earlier paper (12), both of which have been used as source material for the above. Reference (9) provides a comprehensive coverage of pacing, including the scientific aspects of pacing and the differences between pacing and graded exercise.

Pacing is one of the most effective ways to help reduce symptoms of ME/CFS and Fibromyalgia including depression, anxiety, fatigue, and pain and can assist to improve quality of life. Establishing daily pacing routines within a person's individual energy envelope is critical. To improve your health status it is also important to stop using a push/crash cycle (CFIDS Self Help).

For more information on 'pacing', see Fact Sheet 4: Learning to 'pace'

<http://www.mecfs.org.au//media/files/factsheets/English-Sheet4.pdf>

Countess of Mar



ME/CFS

In the summer of 1989, while dipping her sheep through a tank of organophosphorous chemicals, Lady Mar was subjected to a splash of chemicals on her foot, and three weeks later developed headaches and muscular pains. She was eventually diagnosed with Chronic fatigue syndrome. Since then Lady Mar has used her seat in the House of Lords almost exclusively to press the government to provide suitable care and support for patients with similar long-term and poorly understood medical conditions, and to better regulate the use of organophosphates. This also led to her membership on the EU sub-committees.



<http://www.forward-me.org.uk>

As a consequence of her illness, Lady Mar founded the organisation Forward-ME to co-ordinate the activities of a fairly broad spectrum of charities and voluntary organisations working with patients with chronic fatigue syndrome, which is also known as Myalgic Encephalomyelitis (ME).

Speech made by Countess Of Mar 18th March 2015

<http://www.forward-me.org.uk/Speeches/ROYAL%20SOCIETY%20OF%20MEDICINE.pdf>

55 Reasons why it is difficult to treat a person with Very Severe ME



By Greg & Linda Crowhurst 18th March 2013

All the time that ME is treated only as a fatigue illness the health needs of the very severely affected, who feel unimaginably ill in every moment, who are not generally part of research and whose experience is poorly if at all understood, are massively at risk, for some of the following reasons; this is not an exhaustive list by any means :

1. It is impossible for the person to travel to a clinic or a hospital.
 2. It is extremely difficult to find a knowledgeable GP or consultant .
 3. There is little, if any choice of biomedical ME consultants.
 4. Knowledge of how to approach or communicate with a person with Very Severe ME is minimal.
 5. The system expects people to fit into it and is not very accommodating of those who cannot.
 6. Hypersensitivity to touch makes physical contact unbearable, dangerous, impossible without harming the person with Very Severe ME.
 7. Hypersensitivity to noise makes it difficult to impossible to bear the sound of the voice of the GP or consultant, let alone all the background noise and any other noise exposure.
 8. The impact of noise may cause the person to be damaged and physically harmed for weeks, months, even indefinitely.
 9. The impact of chemical sensitivity means the person cannot go into environments where ordinary cleaning agents, perfumes, chemicals are used.
 10. The person with multiple chemical sensitivity cannot bear to be in the presence of people wearing perfume on their body or clothing. It will harm them and cause increase in symptoms. They cannot afford to have anyone visit them and bring their perfume and chemicals into their house, without dire consequences.
- *****
11. Light sensitivity may make it impossible for a person to be in a room with ordinary light. Exposure to light can be agonising and harmful.
 12. It may be impossible for a consultant to examine a patient or write notes or see instruments in low to dark light, which is the only way a person with Very Severe ME can be seen; even the noise of a pen on paper can be too much to bear.
 13. Cognitive issues make it difficult for the person to remember what needs to be said, to access information within their mind .There are blocks on every level of communication in Severe ME. Communication requires inward and outward pathways to function properly; these are not there, reliably or at all, for the person with Very Severe ME.
 14. Processing difficulties in the brain make it difficult to impossible to understand questions or information and to answer adequately or comprehend meaning. Any mental demand can lead to massive deterioration: instantly.
 15. There is not enough energy for the person to explain their history and symptoms or express their concerns about their health, even if the person can temporarily access it. The effort of speaking, if the person is able to speak, is too much and can lead to a post-exertional crisis. The full reality of a person's disability and illness experience can be missed if the moment they manage to

communicate is considered the norm, when it is in reality rare to impossible.

16. Extreme pain and physical discomfort make it difficult to concentrate and deal with complex interactions with other people, especially as the interaction itself will most likely increase the pain even more.
17. Paralysis makes any interaction impossible, you cannot function when you are completely paralysed either mentally or physically; you cannot even speak or open your eyes. Transient awake paralysis can hit any muscles at any moment.
18. Drug sensitivity and allergy make it risky to even attempt to try and take new drugs and nutritional medicine, even if needed.
19. Any drug at normal dose is likely to be too high for the person with Very Severe ME or may not be tolerated at all, even at a lower dose.
20. If regular injections are suggested/required, the treatment may not be accessible because of skin sensitivity, pressure sensitivity, neurological and muscle pain, hyperesthesia, the risk of intolerance of the drug, the inability to cope with another person in the room, the noise and chemical exposure, the energy required to interact, is unlikely to be there. If the person is required to be in a different posture, it is likely to be impossible for them and can endanger their health to try.

21. A blood pressure cuff can be too painful to put on and bear the increased pressure, as it is pumped up. Harm can be done if this is ignored.
22. Taking blood samples, may be difficult to impossible, in any one moment, especially if you have to apply a blood pressure cuff and the person cannot bear it. Increased pain and exacerbation of symptoms as a consequence may be persistent. Veins may be hard to find or persistently collapse, causing additional stress and difficulties gaining enough blood. Pain may be so extreme that the additional pain of a needle puncturing skin may be too much to tolerate. Extra time and flexibility are always required, plus a willingness to adapt to the persons physical reality.
23. The weight and pain of a cannula pressing on hypersensitised painful skin and muscles may be intolerable.
24. Various different postures required may be impossible to achieve for examination.
25. Physical contact itself, required for physical examination, literally causes deterioration of symptoms and increased pain, spasms, paralysis, cognitive dysfunction to worsen. There will always be a post- exertional reaction, which is essential to consider and take into account and can be extreme and lead to massive deterioration and distress.
26. Providing a urine or stool samples is not the simple act that it is for ordinary physically functioning people. How is the person to capture the urine or stool with paralysed or numb hands with poor co - ordination, spasms, muscle dysfunction. How is the person to understand instructions with severe cognitive dysfunction similar to Alzheimer's?
27. Any test or treatment involving equipment is likely to be impossible to manage and potentially harmful from over exertion which leads to cognitive and physical deterioration and risks the persons ability to tolerate or cope with any deterioration especially if the impact lasts months or years. The health of the very severely affected is so frail that inappropriate intervention can even lead to death.
28. Two way communication may be impossible and even if possible will be limited complex and potentially harmful, leading to severe post- exertional impact. It is essential that anyone trying to communicate with a person with very severe ME understands the way the person communicates, what they can tolerate and how little energy they have and not ignore or forget the persons reality.
29. Experimenting with treatment is a very high risk strategy without knowing if the person will be able to tolerate recommendations and without understanding possible reactions. Should never be undertaken without due consideration of risk and possible side affects with careful consideration of possible impact in advance with a strategy in place to support the person should they choose to go ahead. People with very severe ME are desperate for help and so open to mistreatment and defensive blaming by professionals who simply have not understood the

frailty or risk. They are at massive risk of deterioration and harm being inadvertently or carelessly done to them; for this reason a proper Risk Assessment should always be performed.

30. There are no NHS medical consultants, that we are aware of, to turn to, who have the necessary medical knowledge and experience, or who are willing to travel to the home, in the UK currently – there is little hope of finding one . So many symptoms of the most severely ill are either ignored or dismissed and overlooked and not properly understood.

31. The knowledge base required to safely and adequately suggest and provide tests, treatments, ongoing support, for Very Severe ME with complex neurological dysfunction is apparently not available within the NHS currently or if it is, it is inaccessible to the most profoundly disabled and severely ill patients, with an ME label. It is not adequate to state ME is a fatigue condition and ignore swathes of symptoms that are profoundly disturbing, distressing and due to real physical dysfunction, which would be taken gravely seriously in other illnesses, such as stroke, heart failure, diabetes, cancer and other more rare genetic and other diseases. There is an associated confusion with what is co-morbid and what is ME – there does not seem to be a universal holistic, medical approach to the complex interaction of symptoms.
32. There is a need for partnership, in working out how to offer medical support and assistance safely. There is a need for humility and an ability to admit ignorance, lack of knowledge and to take responsibility for actions and reactions and wrong treatments and methods, especially a need to comprehend the very real risks and dangers of deterioration and opposite reaction to that hoped for or desired, that again we have rarely found.
33. A person with Very Severe ME is unlikely to tolerate or cope well with the physical demands of invasive treatment, even if required.
34. A person with Very Severe ME is likely to be extremely drug sensitive ; they require an awareness of anaesthetic sensitivity that is generally not provided by professionals. The person and/or their carer is more often put in the situation of having to guess what is safe, as professionals are themselves seem unaware. How can they be given safe advice when their symptoms are not adequately investigated or properly medically explained, in the first place ?
35. People with Very Severe ME just cannot access everything required to negotiate with doctors surgery and hospital settings, treatments, follow up appointments, Physiotherapy, OT, medical assessments, operations etc. They are at grave risk of harm because of the dearth of aware medical consultants to back them up and make safe recommendations.
36. People who live away from direct contact with public places and people due to profound hypersensitivity and fragility are extremely vulnerable to exposure to infections and less able to fight them off, risking increased deterioration of health if they catch anything.
37. Because of the confusion and collusion with the psychiatric lobby and the wrongful focus purely on fatigue, it is extremely difficult to know who it is safe to trust and who will not harm you. Harm can be done through lack of understanding or misdirected interpretation of illness and lack of understanding of how to help the most severely affected, whose physical experience is so much more extreme and complex than those mildly affected, whom professionals are more likely to have encountered if at all.
38. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to misinterpret.
39. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to misrepresent in a health service determined to focus on a psychosocial interpretation. The current NHS pathway is woefully inaccurate and inadequate.
40. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to misunderstand.

41. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to mistreat.

42. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions, are easy to have wrong and inaccurate reports written about them, expressing opinions as fact; wrong opinion based on lack of knowledge – this can do much harm.
43. There is not enough accurate, adequate explanation or study of individuals symptoms to help identify them accurately, or protect people with Very Severe ME and provide informed documents to help inform others.
44. Private tests and treatments are often too expensive to conduct.
45. Private consultants are often too expensive to pay for home visits, even if willing.
46. The person with Very Severe ME is physically profoundly ill and often cannot undertake the risk of trying to get help, from an unknown consultant or doctor, when any interaction and effort leads to profound consequences of health deterioration, temporary or permanent or very long term.
47. Hospitals, outpatient departments and doctors surgeries are not generally geared up to accommodate multiple chemical sensitivities, noise sensitivity, light sensitivity, need for bed rest etc. Being exposed to the major physical trauma of travel and then being exposed to so many people, interactions and so many sources of noise and chemicals and infections will be too much for the person with Very Severe ME.
48. Sitting and standing or tilting will be extremely difficult to impossible for the person with very Severe ME and could endanger their health or be intolerable and harmful to attempt.
49. Even lying down may be extremely uncomfortable and painful, even if this is necessary or unavoidable.
50. Even tolerating a wheelchair may be too physically uncomfortable and complicated for the person to use, despite the apparent need. There are complex symptoms affecting multiple systems, resulting in difficulties with motion, reversal of direction, vibration, noise, posture, speed and pain, dizziness, visual disturbance.
- *****
51. Travel is a nightmare for the person with Very Severe ME. Motion, bumps, noise, vibration, smell of chemical and upholstery, petrol, perfume , exposure to light, are intolerably difficult to bear. Sitting up may be unachievable. Travel lying down may be impossible and impractical. It may be impossible and dangerous to attempt. There will always be a profound post- exertional reaction. Toilet stops will be complicated , on many levels or impossible to deal with.
52. Some people are so pressure touch sensitive, so hypersensitive and in pain that they cannot tolerate any noise protection, such as ear phones or ear defenders or ear plugs. Physical contact can literally harm them. They have no choice but to remain in a protected environment, with noise reducing curtains and triple sound proof glazing, sound proofed walls and doors etc. It is extremely difficult and challenging to reach out to such sensitive people, whose reality is virtually unimaginable.
53. Pills and capsules are often not made of easily digestible materials,such as gelatine. Medicines may have ingredients that are not tolerated and can exacerbate food sensitivities and gastric issues, which are already severe to extreme in this extremely ill group of people. The NHS does not appear to accommodate this issue well.
54. Even with the best intention, medically knowledgeable consultants and safe pathways, are simply not there currently, nor have they been, in our experience of over two decades of seeking them within the national health service in the UK.
55. This is an illness that is extremely difficult to comprehend from the outside. With such complex cognitive dysfunction and blocks upon every level of communication, it is extremely hard to explain and articulate and identify the profound level of dysfunction from the inside. Reactions are often confusing and opposite to what would normally be expected to occur, so confounding the help that should be available but cannot sadly be accessed, rendering the people most in need, invisible and living secret tormented lives.

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Please fill in the form and return

Thank You

Membership Secretary

MESiG on Social Media



Please 'Like' our Facebook page:

ME Support in Glamorgan M.E.S.I.G



Follow us on Twitter:

@MesigWales



Send us a message:

Mesigwales@gmail.com

Visit our Website:

www.mesupportinglamorgan.co.uk

Contact and Support

ME Association

7 Apollo Office Court,
Radclive Road,
Gawcott,
Buckinghamshire
MK18 4DF

Tel: 01280 827070 10am - 3.30pm

Email: meconnect@meassociation.org.uk

Website : www.meassociation.org.uk

25% ME Group

21 Church Street
Troon
Ayrshire KA10 6HT

Tel: Office 01292 318611

Advocacy line: 01292 312369

Website: www.25megroup.org

ME Connect

Helpline 08445765326

10am-12pm, 2pm-4pm, 7pm-9pm weekdays

STIFF (UK)

PO Box 1484
Newcastle-under-Lyme
Staffordshire, ST5 7UZ

Tel: 01782 562366

National ME Centre

Disablement Services Centre.
Harold Wood Hospital
Gubbins Lane
Harold Wood
Romford
Essex, RM3 0BE

Tel: 01708 378050

Website : www.nmec.org.uk

Brame

30 Wimmer Avenue
Winterton-on-sea
Great Yarmouth
Norfolk
NR29 4BA

UK **Tel/Fax:** 01493393717

Email: info@brame.org

Action for M.E.

PO Box 2778
Bristol
BS1 9DJ

Membership/general: 0845 123 2380 /
0117 9279551

Mon - Fri: 9.30am - 5pm

Telephone support: 0845 123 2314

Mon - Fri: 11am - 3pm

Welfare rights helpline: 0845 122
8648 (Membership only service)

Monday: 1pm - 5pm

Tuesday: 9.30am - 12.30pm & 3.15pm
- 6.45pm

Wednesday: 1.30pm - 4.30pm

Thursday: 9.30am - 1pm

Friday: Closed

Email: admin@afme.org.uk

Website: www.afme.org.uk

MCS Matters

(Multiple Chemical Sensitivity)

Gordon D McHenry

UK Co-ordinator

Global Campaign for recognition of MCS

Tel Helpline: 01446 794 700

Tues & Thurs 2—4 and 6—7pm (manned
when able)

Contact and Support continued

Fibromyalgia Association

PO Box 206
Stourbridge
West Midlands
DY9 8YL

Helpline:

Tel: 0844 887 2444 (10am - 4pm Mon - Fri)

Email: fmauk@hotmail.com

The Young ME Sufferers Trust

PO Box 4347

Stock
Ingatestone
CM4 9TE

Tel: 0845 003 9002

(best between 11 –1 and 5—7pm week-days)

Website: www.tymestrust.org

Welsh Association of ME & CFS Support (WAMES)

Tel: 029 20515061

Email: enquiries@wames.org.uk

Website: www.wames.org.uk

C.L.I.P-

Coping and Living in Pain, support group.

Tel: Richard Goss, 01443 757378

Gloria Edmunds, 029 20530593

Steve Sweetman, 02920214339

Email: pain.help@ntlworld.com

Association of Young People With ME (AYME)

10 Vermont Place
Tongwell
Milton Keynes
MK15 8JA

Email: info@ayme.org.uk

Tel: 08451 23 23 89

10am-2pm Mon-Fri

Website: www.ayme.org.uk

Useful Telephone Numbers

A range of useful information leaflets can be obtained from any of the groups.

Benefits:

Citizens Advice Bureau

Tel: See telephone directory for nearest office

Website: www.citizensadvice.org.uk

Dial UK (Disability Information and Advice Line services)

Tel: 01302 310 123

Website: www.dialuk.info/index.asp

Benefits Helpline

Tel: 0800 88 22 00

Social Care:

Assessment Centre

Will help with occupational therapy and evaluations

Tel: 029 2052 0984

Occupational Therapy:

Tel: 029 2076 7404

Contact and Support continued

Travel

National Rail Enquiries

Tel: 0845 748 4950

Disabled assistance

Advance notice is required by the train operator.

Bus and Coach:

National Express

Tel: 0870 580 8080

Travel Line

Tel : 0870 608 2608

VEST: for help with local lifts and transport for the disabled - *Ring* 029 20490325 and ask for an information pack.

Carers Line

Tel: 0808 808 7777

The Samaritans

24 hour confidential and emotional support helpline and email service for anyone in crisis.

Tel: 0845 90 90 90

Email: Jo@samaritans.org

A 4 ME

Third Floor
Canningford House
38 Victoria Street
Bristol
BS1 6BY
Tel: Lo-call 0845 123 2380 or 0117 927 9551
Fax: 0117 9279552
Email: admin@afme.org.uk

Website: <http://www.a4me.org.uk>

Welsh Association of ME & CFS Support (WAMES Young People)

Michelle Penny

Tel: 029 20515061

Email: michelle@wames.org.uk

Website: www.wames.org.uk

(**Carers**—same as above but contact
Sylvia Penny—same tel no.

Benefits advice and Support

If you are having problems with your benefits, need some advice or your benefit entitlement checked, you might like to get in touch with one of the three listed below.

The Law Centre

41-42 Clifton Street

Adamsdown

Cardiff

TEL: 029 20498117

Drop in: Monday, Wednesday, Friday

10-12.30

Tuesday, Thursday 2-4.30

Phone advice: Monday and Thursday

Speakeasy Advice Centre

166 Richmond Road

Cardiff, CF24 3BX

TEL: 029 20453111

Riverside Advice

41a Lower Cathedral Road.

Cardiff

TEL: 029 20341577

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Tel: 07786147681

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Dee Penny (Treasurer)

Tel: 02920842499

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Email: rob.goodmanTHR@hotmail.co.uk

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Mary Jones

Tel: 07954200841

Email: dh.jones94@ntlworld.com

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*Please send us anything you wish us
to submit in next newsletter: poem,
recipe, personal story, question etc.*

or email

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Irenedavies01@hotmail.com



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