DGMEFM Network

Support for ME, CFS, Fibromyalgia

December 2019

Welcome all,

Another year draws to the close. I find that these dark days are not good for the mood, and being in the cold seems to enhance the pain, but for me at least, it's probably better for the ME, as I'm less likely to be outside and overdoing it physically. It's been a year of two halves for me. A pretty decent time through until May, followed by a pretty awful relapse, that I'm only beginning to pull out of now.

It's been a hopeful year for research with some exciting news coming from the USA and Australia. As always there's a step or two forward and one back… but science is advancing and is getting more difficult to ignore for the doubters.

Christmas and New Year can be a struggle for us. At times we can feel we are missing out. Please know that you all are in our thoughts. Enjoy as much as you can. If you can't do the big occasions take pleasure in the small things – and reach out to your fellow ME and fibro friends too.

Wishing you all a merry Christmas and a happy, healthier 2020 – when it comes.

Craig Woods

Monthly Get-Togethers

First Thursday of every month 1pm – 3pm at Midsteeple, Dumfries

Dec 5th Our usual cuppa and chat, and welcome to new members. Suggested discussion theme: 'Christmas and New Year – what do you do to enjoy this time, and to manage yours and others' expectations over the festive period?' Kerry Morrison from The Stove, will join us around 2pm to explore what we might like from a possible project with an artist.

Jan 2nd We will **not** be meeting on this occasion as the Midsteeple is closed for the holidays, but see the January 9th pop-up meeting below.

Feb 6th Our guest will be Emma Munro from the Citizens Advice Bureau (DAGCAS) for an update and general questions on benefits, the support the Bureau can provide, and how to best help us when using their service.

Refreshments will be provided at the Midsteeple meetings. Entry is through the Box Office door. We use the meeting room on the 1st floor. Press and hold the lift button to call it and press and hold the button until the door unlocks on the 1st floor.

Pop-Up Meetings

Dec 8th Sunday From 1pm. Join us for a Xmasy lunchtime get-together at **Castle Douglas Garden Centre Coffee Shop**. The Centre is on the edge of town heading out on the Dalbeattie road.

Dec 14th Saturday From 1pm. **Xmas lunch at Mabie House Hotel.**

Please let us know in advance if you hope to come to either of the Xmas lunches.

Jan 9th Thursday From 1pm. As we are not able to meet on 2nd Jan, this will be a get-together at **Garden Wise Coffee Shop**, Castle Douglas Road, Dumfries. Let us know if you need a lift from town.

Jan 24th Friday 7:30pm. Fibro My Arth! comedy show. **Theatre Royal** See page 6 for details.

Look out for other pop-up meetings on our Facebook page or website meetings page.

Contact us:
Phone/WhatsApp - 07437 602610
email - admin@dgmefm.org.uk

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Gift Day thanks

Many thanks to all who contributed to our ‘Gift Day’. It’s a great help towards meeting the costs of the newsletter and our other expenses. If you haven’t already done so, please consider signing up with Easyfundraising https://www.easyfundraising.org.uk/causes/dgmefmnetwork/ and with AmazonSmile https://smile.amazon.co.uk/ch/SC030641. We would then receive a small percentage from your on-line purchases whenever you shop through them, and at no cost to yourself. We are registered with Easyfundraising as ‘DGMEFM Network’ and with Amazon Smile in our full title ‘Dumfries & Galloway ME and Fibromyalgia Network’. Thank you.

Pacing With Fibromyalgia & Chronic Fatigue Syndrome

This is an article by Adrienne Dellwo in www.verywellhealth.com ‘Living with CFS and Fibromyalgia’, updated October 2019.

When living with fibromyalgia (FM) and chronic fatigue syndrome (ME/CFS), pacing is key to managing your symptoms. With the busy lives most of us lead, that's easier said than done! Still, with some effort, you can learn to pace yourself. And you'll be glad you did.

Why Is Pacing Important?

FM and ME/CFS can really sap your energy. When your energy is low, everything you do takes a greater percentage of the whole. As you've probably learned the hard way, when you overdo it, you pay a steep price in heightened symptoms. Many of us push ourselves on good days, trying to catch up on everything we can't do the rest of the time. In one day, we'll do multiple loads of laundry, clean the kitchen, weed the garden, and go to the grocery store. When symptoms start to kick up, some of us push harder, feeling like we have to get everything done before we're in too much pain to keep going. But the only thing that does is make us worse. What good is one productive day when it leads to three (or ten) on the couch? Once you realize that the push-crash cycle isn't working, you're left asking, "How can I get stuff done without making myself worse?" The answer is pacing. It takes practice, but after a while, it gets to be second nature.

How Do I Pace Myself?

A lot of pacing strategies can help you live better with your condition. They include: Knowing your body; Short activity periods; Scheduled rest; Routines; Prioritizing; and Switching tasks. Don't feel like you need to use them all—experiment and see what works for you. Below is a closer look at each strategy.

Knowing Your Body

To be successful at pacing, you have to pay attention to your body and know your limits. It can help to keep a journal or symptom log. Your goal is to answer these questions:

- How much physical activity can I handle in a day (or in one stretch)?
- How much mental exertion can I handle in a day (or in one stretch)?
- What activities impact me most?
- At what time of day do I have the most energy?
- What symptoms are "early warning signs" that I've neared my limit?

Once you know these answers, you're ready to apply pacing techniques to your life.

Short Activity Periods

We're sprinters, not marathon runners. If you have a big job, don't try to plough through it for hours. Work for a short time, rest for a while, then work for another short period.

The amount of time you work and rest depends on your capacity for activity. Start with shorter periods than you think you can handle, and rest for at least 15 minutes in between. Set a clock so you don't get caught up in it and go for too long. See how you feel after a couple of days, then adjust times until you've found the right balance.

When you are resting because you are worn out, you need to remember that you are not wasting the day doing nothing. You are doing exactly what you need to do. You are recovering.

Scheduled Rest

Scheduled rest periods are more than the short breaks you take between bursts of activity. Instead, it's time built into your day when you can take a nap or get some real rest. Again, the length of time is something you have to define for yourself. Lying down for half an hour may give you a nice boost, or you may need a two-hour nap. Your scheduled rest period is not the time to check e-mail, pay bills, read, or make your grocery list. Your mind needs rest just like your body. Try sleeping, lying quietly, meditating, or taking a hot bath.

Routines

Routines can really save you, especially if you have a lot of brain fog. If you establish and stick to a routine as much as possible, it helps prevent problems like pulling weeds all morning and then realizing you need to go grocery shopping. The biggest barrier to routines is that our conditions are unpredictable. We rarely know when we'll have bad days or when a good day will take a turn for the worse without warning. To deal with this unpredictability, build in flexibility. Look at your average energy and under-schedule each day based on that. If you finish up and still have energy, you can work ahead. When you have a few down days, catch up over the course of several days, re-prioritizing to take care of the most important things first.

Prioritizing

Priorities are crucial to pacing. Try to have a clear picture of what absolutely must get done in a day, and focus your energy there. If less important things need to wait as a result, then that's just how it is. If you find yourself feeling as if too many things have to get done in one day, make a list and then break your list into three parts: needs, wants, and shoulds.

- "Needs" are top priority, have-to-get-done-right-now-or-there-will-be-consequences things.
- "Wants" are things that you'd really like to do IF you have the energy.
- "Shoulds" are things you feel like you ought to do to please someone else or because other people would do them (such as, "I should cook a big, elaborate meal on Sundays because my mom always did.")

Take care of your "needs" first, then move on to the "wants" (again, IF you have the energy). If you can't get to the "shoulds," so be it. The "shoulds" can be a big source of guilt, because by not doing them, you may upset or disappoint someone. Good communication about the limitations of your illness can often help with this by adjusting other people's expectations about what you're able to do. You may also need to educate people in your life about your illness.

Switching Tasks
Instead of doing one thing for a long time, try to change the type of activity frequently. If you do one physical activity for too long, it can tire out the muscles you're using, which may lead to pain and fatigue. This goes for both physical and mental activities. For example, say you need to wash dishes, fold laundry, pay bills and return some e-mails. Don't do them in that order! Instead, wash dishes, pay bills, fold the laundry, then work on e-mail. By alternating physical and mental activities, you give your brain and muscles the rest they need. (And don't forget that you may need rest periods in between each activity as well.)

It's an On-Going Process! Pacing takes some effort and self-discipline on your part. Once you see the difference it can make, however, you'll find that it's easier to pace yourself than to deal with the consequences of NOT doing it.
https://www.verywellhealth.com/pacing-yourself-with-fibromyalgia-and-mecfs-715723

Pacing discussion at our September monthly meeting

Of those at the meeting all experienced fatigue as an immediate consequence of exertion, with the delayed (PEM) effect kicking in the next day for around half of those there and on day 2 for the other half.

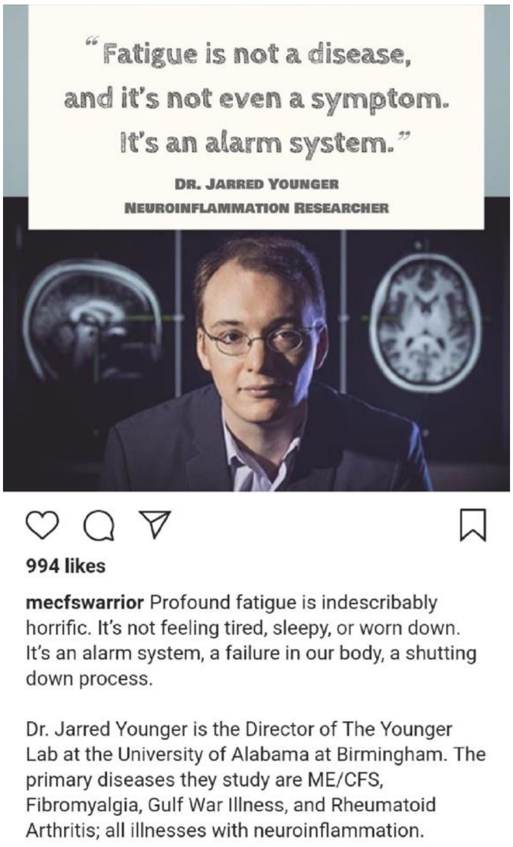
It’s not all physical. Remember that mental and emotional exertions are exhausting. Remember to pace yourself with these too.

Try to find your baseline. This is especially important for those on constant painkillers who may not get the warning signs to slow down.

What can be managed relatively easily one day can be too much on another day. So many factors affect this, including environmental and bugs and infections. Reduce your fixed commitments to the minimum and try to be flexible enough with what you need to do so that you can do it when feeling ok.

Keep your heart rate low. Relaxation, deep breathing and yoga can help. Fitness trackers with constant heart rate monitoring can sound a warning when it gets above the level that you find causes PEM. For me that’s around 85bpm, but varies for everyone.

Craig



“Fatigue is not a disease, and it’s not even a symptom. It’s an alarm system.”

DR. JARRED YOUNGER
NEUROINFLAMMATION RESEARCHER

mecfswarrior Profound fatigue is indescribably horrific. It’s not feeling tired, sleepy, or worn down. It’s an alarm system, a failure in our body, a shutting down process.

Dr. Jarred Younger is the Director of The Younger Lab at the University of Alabama at Birmingham. The primary diseases they study are ME/CFS, Fibromyalgia, Gulf War Illness, and Rheumatoid Arthritis; all illnesses with neuroinflammation.

Committee News

At the AGM in September, Kim Jacobsen, our former secretary, stood down from the committee. Kim has contributed a lot to us in her time on the board. Besides being an incredibly efficient secretary, a huge job in itself, she has produced and collated our survey, designed our leaflets and business cards, and still found time to create some wonderful jewellery to sell to help our funds.

Thank you, Kim for all your hard work and advice. Enjoy your retirement from the committee!

Hello ME

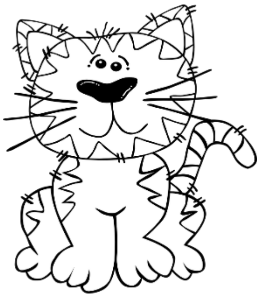
Hello said ME, I’ve come to stay
You’re going to live a different way
So tell your friends, and family too
Of what they might expect from you

Some may say it’s in your mind
Some be cruel, and others kind
You’ll need to choose the one’s to lose
Their attitude just drains you
And those you feel are worth the fight
Who care enough about your plight

Shops, cafés and busy venues
Too much noise can overwhelm you
Make brief encounters your new basis
And see your friends in quiet places
Go whenever suits you best
Don’t compromise your need for rest

Lost for words, or words just lost?
A fog to get your thoughts across
A blank to fill, your words to gel
A punctuated tale you tell
Some quiet time and then you’ll find
The fog to lift and clear your mind

I’ll flare up if you overdo it
It’s true, there is no silver bullet
No fix to take ME in your stride
Slow down your pace, set jobs aside
In time you’ll come to understand
Don’t let ME get the upper hand



The world of work you left behind
The ‘what you do’ now undefined
Retired ill, put out to grass
Embracing this new circumstance
Take it as a second chance
See what you’re able to enhance
To bring your life to balance

Learn now to accept ME
Find how best to cope with ME
And don’t give up ambition
Acceptance, not submission
You’ve time to learn new skills
Within your reach, and able to fulfil
Look to what you can do
And each day will bring value

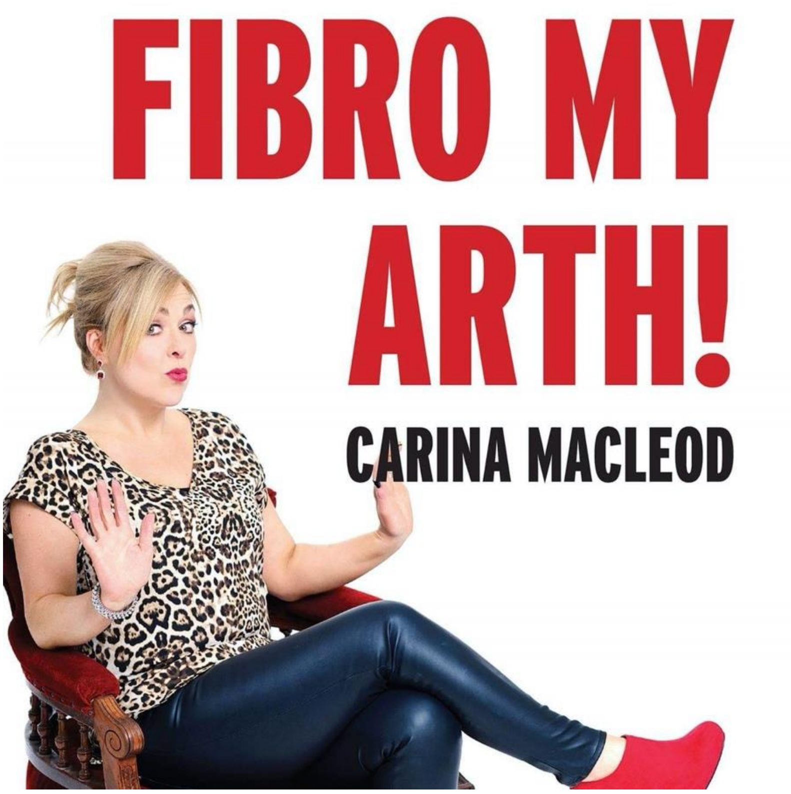
My name is ME, I’m here to stay
And we can live in a different way
Day by day…….by each new day

Hummingbird – overcoming difficult times

Paul Thompson

Comedy Inspired By Fibromyalgia Comes to Dumfries

I guess I should introduce myself first. My name is Carina MacLeod. I'm a stand-up comedian and two and a half years ago I was diagnosed with Fibromyalgia and osteoarthritis. When the consultant rheumatologist confirmed it, I just burst out crying. For me that was pretty much how I felt. My life was going to be completely different. I had visions of wheelchairs, and houses with no stairs. I also thought that my husband hadn't signed up to marrying someone who was going to get decrepit before their time. How on earth was I going to cope with this life-changing news? I was 44 years old at the time.



After wiping away the tears and snot I decided "f**k it!" I'm going to write a stand up show about Fibromyalgia. Where on earth would I start though? I could hardly say the word, never mind spell it. How could I find the funny in Fibromyalgia? Was it actually possible to do such a thing? Apparently anything is possible if you put your mind to it, so that's what I did.

I looked back on when I became unwell, and took it from there. The show is very personal, it is self-deprecating but in such a way, that someone who suffers with a chronic illness perhaps has had the same experience or feelings, and knows exactly what I'm talking about. Don't get me wrong, this is not a comedy show exclusively for the chronically ill, or just those with an invisible illness. It is also for those who love stand-up comedy. They are just being quietly educated at the same time. If you don't speak about it to raise awareness, how will people know what it's like?

Now it's not for the faint-hearted, as I do go into detail about bodily functions and how Fibromyalgia affects us physically and emotionally. I can't really give too much away, you'll have to come along to see the show yourselves. It is a 90 min show, split in to two halves of 45 minutes. I wouldn't expect myself to try and hold a pee for 90 minutes without a break, far less anyone else.

Fibro My Arth! Is on at The Theatre Royal, Dumfries on Friday the 24th of January at 8pm.

Tickets are available from the Theatre Royal's own box office. Tickets are £15 but Carina has kindly offered a discount for Network members - see posted issue. If purchasing tickets online there is a booking fee of £2.

Meet us for a pre-show drink in the theatre bar from 7:30pm

Network Membership

Our membership roll continues to slowly increase. The higher the numbers we have, the louder our voice is when we are representing the interests of fibro and ME/CFS sufferers in the region. Recently we have had a few members asking to leave the Network because they "can't attend meetings". There is no need or obligation to attend meetings to be a member. Please don't feel you have to, and if you don't want to we completely understand. By remaining a member you can continue to receive the postal newsletter (if you wish) and show the need for better support to the NHS, politicians and more organisations.

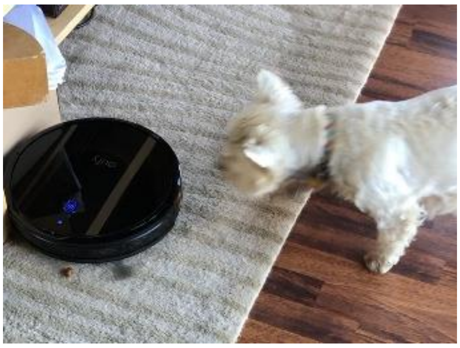
We understand that our meetings are centred on Dumfries and Castle Douglas. Unfortunately we don't have people to host meetings elsewhere. If you would like a meeting or get-together in your area please get in touch. You'd need to be able to choose a venue – a café is good – and be reasonably sure you can be there on the day and time given. We will happily promote it. We have a nice wee community of friends meeting up and supporting one another in Dumfries and the CD area and it would be lovely to spread this to other parts of D&G.

Making Life A Bit Easier

I am beginning to pull out of one of my longest and deepest relapses of recent years. As ever it is incredibly difficult to see even the basic level of activity diminish even further. It gets me down seeing the work and obligations pile up and as the housework piles up. My home often requiring a clean, yet I can barely scrape my energy together to clean myself… On one of those such days I received an email with a special offer and a 30 day trial on a robot vacuum cleaner. I thought I'd give it a go. My floor has never been so clean. It trundles out and vacuums while I'm in my bed every other night. My wee dog, Fraoch, – who makes more than her fair share of the mess – was not impressed, needless to say – especially when on it's first outing the robovac headed straight for the kibble which she takes to the rug to eat later – and swallowed it before she could! The look on her face was priceless.

In the relapse my eye control has deteriorated with my eyes struggling to retain focus and retain convergence. Another offer pinged in for an Alexa Echo. While I worry about privacy I could see how it'd be useful. It can now read to me, taking the strain off my eyes in the worst times. I can also ask Alexa to ask Robovac to do the vacuuming while I'm tucked up in bed – and if I get cold I don't have to peek out from under my covers to turn the heating up.

After a huge disappointment that the year 2000 didn't bring space hotels and teletransportation I'm finally feeling very futuristic but also very supported by new technology.



Midsteeple Venue

We still don't have any firm news about the future of the Midsteeple as a council venue beyond April. For now our monthly Dumfries meetings continue there as normal. We have an alternate venue in place as a contingency in case the future of the Midsteeple meeting room is not secured. Look out for updates in our next newsletter and online.

New Committee Member

Hi, as a new member to the committee this year, I thought I would introduce myself. I`m 49 years old and was finally diagnosed with Fibromyalgia in July this year. I have suffered from it for the last 4 years but had to take medical redundancy in October.

My hobbies are Mountain biking, walking the dog and reading. If you`re wondering how I still do these hobbies. I`ll let you into a wee secret, I`m still able to Mountain Bike when I`m having a better day due to the fact I now have an E-Mtb. Think of it as a bike with an electric motor, walking the dog is achieved by the use of a class 3 mobility scooter which I use round the local forest paths and the reading I do is when I`ve crashed and need to rest up.

I have now taken over the task of the group blog and wish to carry on the good work of Kim Jakobsen. You can find it at www.dgmefm.org.uk/blog. I am intending adding an image or two of something that relates to each month. This month it will be something Christmassy. With people`s agreement I would like to post photos on the blog from our monthly meetings or other activities we get up to. Last month was the Iris paper folding but I`m unable to post as I do not have the persons authority to put up on a public page. Would be interested to hear your thoughts regarding the use of photos on the blog.

There must be a younger generation out there who are members, who maybe don`t want to attend meetings. I would like you to get in touch as we would love to hear from you on how the group, Facebook Page and Blog could be used in a way to bring you into the group and get you all involved. So if you`ve got any ideas or suggestions please get in touch.

On that note I will finish here. Anybody at all within the group who have suggestions on what you would like to see on the monthly meetings or anybody out there willing to come and show the group your craft or hobby we would love to hear from you.

Stay strong and keep smiling

John Bell

Naltrexone

This past month there’s been discussion on our facebook page around Naltrexone and LDN (low dose naltrexone). This is a drug which has been reported in the past to lessen the pain in sufferers of ME and fibromyalgia.

New research from Australia suggests it can restore the cellular pathways which are disrupted in ME. It also can act as an immunomodulator, and on the opioid receptors, which is possibly why it has the pain reducing function. The research is rather too in-depth for me to begin to understrand fully, I’m afraid. The link to the research is in the November blog.

It is a drug which is not available on the NHS for our conditions but it is easily available (off-license) on private prescription in Scotland – and one of the main research and production centres is located here. It is more commonly used to counter drug addiction. Some of our members have tried it for their ME and fibro.

One member wrote:
“My daughter has been on LDN for over a year and a half. It has helped her with pain and cognitive issues massively. Unfortunately, we can only get it privately at the moment. You do have to build up the dose slowly, and so the benefits take a little while to show themselves. There are no withdrawal issues if you decide to stop - it's not addictive. I have spoken to people who have been taking it for 10 years with no issues at all. I hesitated for a long time before agreeing she should try it, but now I would recommend it to anyone. It's important to understand that you are taking a tiny, very diluted amount of this medication. My girl was tipping into the very severe category of this illness, which is why we went for it, she could barely move or talk, this medication has given her some quality of life back.”

More info at www.dicksonchemist.co.uk/new/clinic-158/ or 0141 404 6255

Please note: this is not a recommendation and anyone considering trying it should consult their GP (who can’t prescribe it) and with a private doctor (who may be able to).

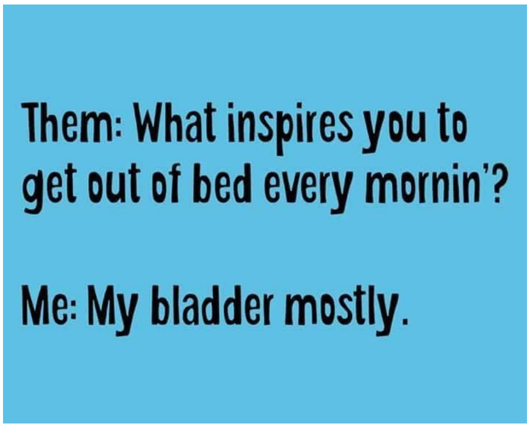
Dr Nancy Klimas Talks About Sleep in People with ME

Excerpt (adapted to show UK drug names) from HealthRising.org of Cort Johnson’s report on Dr Nancy Klimas’ talk.

Dr. Klimas noted that most people with ME/CFS have non-restorative sleep, which derives from a lack of slow-wave sleep that takes place during the deepest sleep stages. That wasn’t a surprise. The surprise was how frequently Dr. Klimas is finding another sleep condition – sleep apnea – in her patient population. A whopping 40-60% of her patients who end up visiting a sleep clinic have at least some element of sleep apnoea. (Since patients with more severe sleep problems are more likely to visit a sleep clinic, that 40-60% is skewed upwards, but since only 3-8% of the adult population has sleep apnoea, the prevalence of sleep apnea still appears to be rather dramatically enhanced in people with ME/CFS.

Sleep apnoea presents a dilemma for physicians since giving a drug that plunges someone into a deeper sleep state could make the apnoea worse and more dangerous. Visiting a sleep clinic isn’t always necessary. Wearing a pulse oximeter (built into many fitness monitors and some smart watches) which measures oxygen saturation overnight can do the trick.

For someone without sleep apnoea, the course is pretty straightforward – get the patient into deeper sleep stages. When faced with a patient with sleep problems, however, most doctors think insomnia and prescribe fast-acting, short duration (temazepan) – “some little Valium derivative drug” as Dr. Klimas put it (:)) that will get a person to sleep – but will not get them into deep sleep. In fact, Dr. Klimas said that valium derivatives Zopiclone and Zolpidem actually “steal slow-wave” or deep sleep and make the non-restorative sleep worse. A lot of her patients, she said, are on the wrong sleep drugs!



Them: What inspires you to get out of bed every mornin’?

Me: My bladder mostly.

The new sleep drugs are mostly hypnotics which were designed to get out of the body as quickly as possible, but Klimas usually wants the opposite – long-acting sleep drugs that help people with ME/CFS get into the deeper sleep stages. That means going old-school with drugs like the antihistamines Benadryl or Nytol or very low doses of tri-cyclic antidepressants (TCAs) (like amitryptiline)– doses too low to affect depression but which can plunge one into a deeper stage of sleep.

Getting a deeper, more restful sleep, is one of the main things I do to help recover more quickly from over-exertion. My doctor is reluctant to prescribe much other than amitryptiline (which doesn't suit me). I've recently discovered a cheaper generic Nytol, diphenhydramine, – which is available without prescription – and as Dr Klimas describes the sleep is less unrefreshing and more restorative than it otherwise would have been. *Craig*

And finally… a funny to end on – with thanks to Shropshire and Wrekin ME support

How to have ME Successfully

- Do not consider having ME unless you have a downstairs toilet
- In order to have ME successfully you should acquire a cleaner, gardener, cook and a general handyman. If this is impossible, you should find a rich, devoted, non-talkative partner with few outside interests.
- It is essential that you should budget and plan for ME as you will require an answerphone, tumble drier, dishwasher and many other supposedly luxury items.
- It is advisable to get rid of dependent children (unless very helpful) and to ask elderly relatives not to have any major crises during the course of your illness
- Pets are a help but they must be self-expressing and quiet. Furriness is a comfort if you have no allergies.
- All visitors should be advised to bring their own food (and some for YOU too). They should also bring bedlinen and take it home to wash.
- Sufferers should buy a new dressing gown fit for public viewing.
- Before embarking on this illness, the would-be patient should make a badge which says 'looks alright, feels awful' and a selection of explanatory leaflets.
- The latter should be carried and distributed on all possible occasions, to protect from any misunderstandings, ignorance and downright nastiness.
- The person with ME (as the most restricted member of the household) should have authority over the TV remote control.
- The person with ME should let it be known that his/her needs will change from day to day, without notice, and family members who help inappropriately will get their heads bitten off.

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