March 2023

DGMEFM Network

Support for ME, CFS, Fibromyalgia

Hello everyone!
Spring has sprung in my garden, with the snowdrops showing their eagerness for the warmer weather. It has been nice to have a few drier days to be honest and to see my garden budding in readiness. I keep my garden fairly natural, I never tidy up after the winter as I like to keep all the wee hidey holes for insects and larvae to survive. There are a family of mice who live under my wonky shed, they keep the local cats entertained scurrying underneath where the cats can't reach. I also have three silkie chickens who live in their coop at the bottom of my garden. One of them has been rather broody of late. I had to move her off the eggs the other day because she had gathered the others eggs to have quite a clutch to brood over. They don't lay every day but they do all lay together, which is interesting to note.

Before Christmas I had a flood in my house, Burst pipes from the upstairs neighbour caused a bit of havoc. The aftermath of that has been damp and mould. There is only so much a dehumidifier can do, and I have had mine on almost constantly for two months. At least it is superficial and not something which requires major renovation.

As a result of all this, I have had such a long spell of chronic asthma, allergy and general autoimmune overreaction. Just got my 6th course of steroids today to try to get it all under control.

When things like this happen, which are out of our control we realise, well I do, that no matter how well we look after ourselves and cope with ME/CFS/Fibromyalgia/Long Covid, it's the curve balls that upset our status quo.

How many times have I said to myself 'I just can't do this!!' recently, then felt inadequate. I don't want to become the high maintenance friend, I want to be capable, and self-sufficient.

But do you know that is a trauma response? I won't go into the whys and wherefores now, but that feeling of wanting to do everything yourself and be a capable person is often a learned behaviour. I have been lucky enough to have counselling over the years and I advise anyone else to request this from your GP. The Adult Mental Health service is there for everyone. Please, make use of it.

My wee grandson has started nursery in readiness for his Mummy to return to work. He's such a confident wee chap. I can see him coming on in leaps and bounds socialising with his peers and having exciting new things to discover. I won't be seeing him until April, when it is his birthday, but I love all the video chats we have daily. He's developed a wave like the late Queen Elizabeth and he babbles away incessantly.

Whatsapp Connection

In January I set up a WhatsApp group for members in and around the Stranraer area in the hope that we can connect with members who are feeling isolated. So far this has worked quite well with a few members having regular chats. If anyone would like to join the group who lives over in the west of the region please contact me on 07557536110 via text and I will add you to the group.

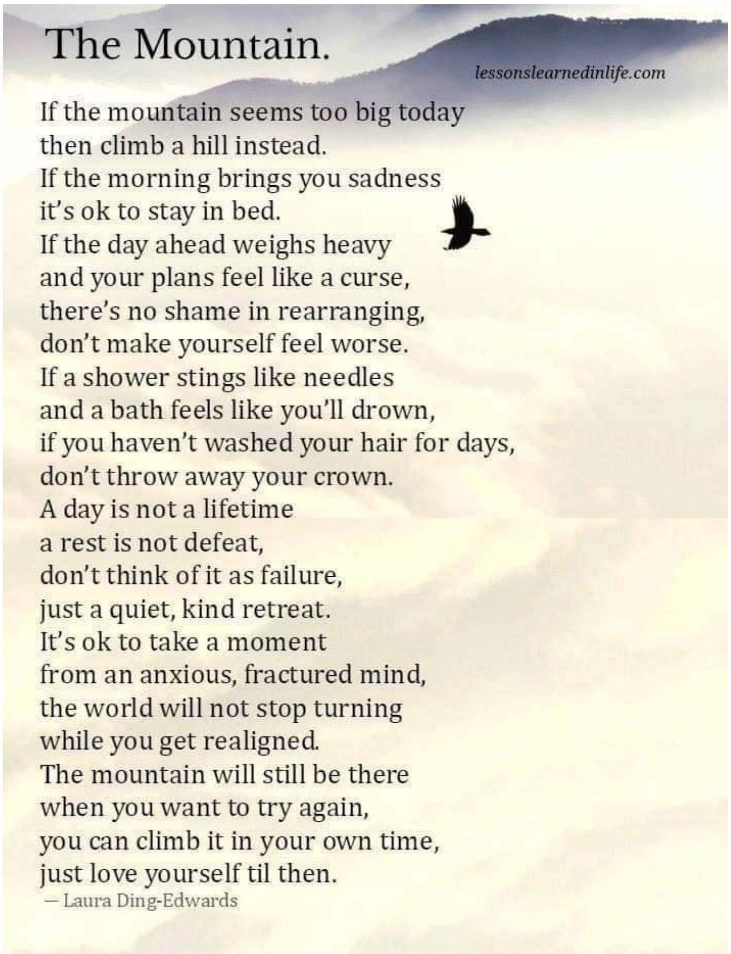
Similarly, I want to organise a WhatsApp group for members in the east of the county. We don't get as much engagement from members in this area and, like Stranraer, I would like to have an outreach for any members who feel isolated or need to be able to chat with like-minded people.

Please get in touch via text on 07557536110 and request to be added to the East group.

The central area of the region has a lot going on and we get good engagement with members. There is the monthly hybrid meeting, which is on the first Thursday of the month 2pm, at Turning Point, Dumfries. We also have a regular group of members in the Castle Douglas/Dalbeattie area who like to meet up now and then. There will be a pop-up meeting at the Crichton in March also.

Hopefully with all this going on, and the better weather on the horizon, we will have a positive and productive summer.

Eileen



The Mountain.

lessonslearnedinlife.com

If the mountain seems too big today
then climb a hill instead.
If the morning brings you sadness
it's ok to stay in bed.
If the day ahead weighs heavy
and your plans feel like a curse,
there's no shame in rearranging,
don't make yourself feel worse.
If a shower stings like needles
and a bath feels like you'll drown,
if you haven't washed your hair for days,
don't throw away your crown.
A day is not a lifetime
a rest is not defeat,
don't think of it as failure,
just a quiet, kind retreat.
It's ok to take a moment
from an anxious, fractured mind,
the world will not stop turning
while you get realigned.
The mountain will still be there
when you want to try again,
you can climb it in your own time,
just love yourself til then.
— Laura Ding-Edwards

Social Meet-Up – First Thursday of the month – in person and online

Join us for a brew and a blether. Come get to know us, chat, ask questions and make new friends. Sometimes we have talks or discussions from outside speakers.
First Thursday of the month. Hybrid meeting on zoom and face-to-face at Turning Point Scotland, Newall Terrace, Dumfries. Join any time between 2pm – 3:30pm.
Sometimes there's even cake!!

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet or go to www.zoom.us on your computer. Enter this info: - Meeting ID: 843 001 5846, Passcode: 2023

Pop-Up Meet-Up

There will be a Dumfries meet-up on 15th March at 11:30 in the Crichton Central Café. Please book at: https://www.eventbrite.co.uk/e/dumfries-meet-up-tickets-524426583027. Thanks to funding from the Communities Mental Health and Wellbeing Fund, we are able to offer a soup and sandwich meal free of charge. Members will need to pay for their own drinks. Check out the website and Facebook page for more pop-up dates / locations over the coming months.

Crafty Friday

One of our Trustees, Corrie, will be hosting this winter's Crafty Friday zoom sessions on the third Friday of every month from 11.30-12.30. The last one before the summer on May 19th, 2023.
During these sessions we can show and share our craft projects, discuss our patterns and techniques, and have a chitchat about crafts, crafting, the weather and the garden etc.

Any member can join this zoom meet. Login details/reminders will be posted a few days in advance of each session on our Facebook “get crafty with ME” Group page.

Look out for updates and Zoom meeting topics and guests on our Facebook page, website or in your email inbox.

Call for new Board members

The Network needs your help!

Over the last 18 months we’ve grown quite considerably. We now have a member of staff (Kalpana – befriending and peer mentoring project officer) and a freelance team member (Eppie – business, admin and management support). We have received funding from a wide variety of sources that is now allowing us to deliver more than we ever have before.

All of this growth, however, means we need more help. We are able to have 12 Trustees on our Board and currently we have 4. The more Board members we have, the more representative it will be of our members’ needs and the more spread out the mental workload of decision-making will be.

We need Board members who are able to attend four Board meetings per year, plus the AGM.
They will also need to respond to emails periodically throughout the year when decisions need to be made in between meetings. There are also opportunities to join sub committees (Communications or Audit and Risk), should you be interested in either of those specific areas of work.

With the conditions of our members, we know it can be hard to take on anything new, so please do not feel any pressure to put your hand up. However, if you, or anyone you know, is interested in joining the Board, please contact Eileen Sangye Longworth by email: eml@dgmefm.org.uk.

You don’t need to have one of the conditions to be welcome on the Board!

What Primary Care Practitioners Need to Know about the New NICE Guideline for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in Adults

Dr Charles Shepherd of the ME Association has co-authored a review of the new NICE guideline. The abstract reads as follows:
“The new NICE guideline for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), published in October 2021, makes significant changes in treatment recommendations. It acknowledges the complexity of this chronic medical condition, which always impacts quality of life and can be profoundly disabling, recognising the prejudice and stigma that people with ME/CFS often experience in the absence of any specific diagnostic test. The guideline outlines steps for accurate diagnosis, recognising post-exertional malaise as a core symptom; importantly, ME/CFS can now be diagnosed after just 3 months in a bid to improve long-term health outcomes. It recommends the need for individual, tailored management by a multi-disciplinary team, ensuring that the wellbeing of the individual is paramount. The guideline makes clear that any programme based on fixed incremental increases in physical activity or exercise, for example, graded exercise therapy (GET), should not be offered as a treatment for ME/CFS and emphasises that cognitive behavioural therapy (CBT) should only be offered as a supportive intervention. Because of the rigorous methodology required by NICE Committee review and the inclusion of the testimony of people with lived experience as committee members, this guideline will influence the future diagnosis and management of ME/CFS in the UK and beyond.”
The full review can be accessed here: https://www.mdpi.com/2227-9032/10/12/2438

Update from Action for M.E.:

If chronically ill people are enjoying themselves, they must feel OK, right? When an important occasion arises, people who are chronically ill have learned to put up with the symptoms of illness, including terrible pain, so they can try to enjoy what they're doing, especially the enriching experience of being in the company of others. Please don't assume that a person who is laughing is a person who is pain-free, ache-free, or otherwise feeling good physically.

Action for ME are continuing to work in partnership with MEAction Scotland, the ME Association and the 25% M.E. group to deliver medical education to health and social care professionals across Scotland and the UK. Through this project they promote a free online learning module on the diagnosis and management of symptoms of ME/CFS. The module is currently being refreshed and will soon be re-launched. This is accompanied by a series of podcasts. They now have six episodes and will soon release a seventh episode on Physiotherapy in the coming weeks.

They have a template letter (included below) that people with M.E. can use to encourage their GP, practice nurse or any other allied health professional or therapist to take the learning module.

They also have a webinar for social care professionals.

Learning module: https://www.studyprn.com/p/chronic-fatigue-syndrome
Podcast: https://www.buzzsprout.com/1717775
Webinar: https://www.youtube.com/watch?v=63MXLuJML1c&feature=youtu.be

Befriending Volunteer Advert

With Kalpana settling in, we're almost ready to launch our befriending service (the peer mentoring service will come slightly later in the year). Below you will find a copy of the befriender role description. If you're interested in volunteering your time, please reach out to Kalpana: kalpana@dgmefm.org.uk

What is the Befriending service?

Having (or waiting for) an ME, CFS, Fibromyalgia or long Covid (with post exertional malaise) diagnosis can lead to people spending more time on their own. This can sometimes mean feel lonely, worried, bored or lead to people missing friends or family.

Our new service will offer free telephone/online and/or face to face friendship services for people with ME/CFS, Fibromyalgia or long Covid (with post exertional malaise), so they can enjoy chatting with someone.

Our service matches volunteers with members to have a weekly phone call of up to 60 minutes maximum. Face-to-face meet ups are also possible depending on the needs of the friend. People can also choose to do a mixture of calls and/or visits. Again, these will be dependent on need and availability.

It's a fun, safe, easy way to get to know someone new from the comfort of your own home.

If you'd like to make a difference to a person's life, read through the rest of this advert and see if it's the right opportunity for you.

What's great about becoming a befriender?

- It's a simple way to give something back through a weekly call/visit.
- Our dedicated team will match you with someone who has shared interests.
- Your calls/visits can make a huge difference to the happiness and wellbeing of a someone.

- We protect the safety of all volunteers and members by making sure that volunteers are PVG enrolled and all appropriate training is given before anyone is matched together.

How does it work?

1. **You sign up** and start your volunteer application. This involves completing references, training, PVG enrolment and having an interview with our team.
2. **We match you** with a suitable person based on your interests.
3. **We will then connect you** to begin your weekly calls.

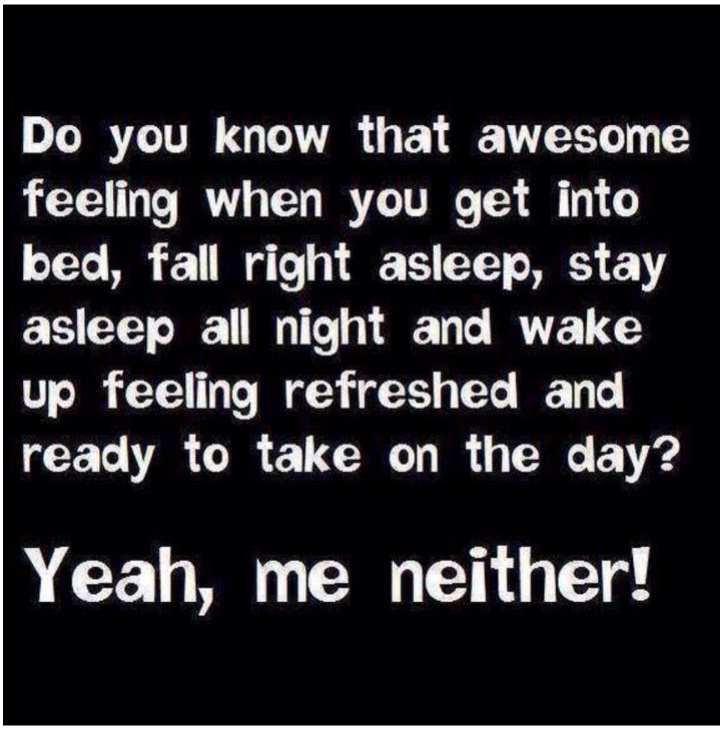
What's expected of me?

We're looking for people who have excellent listening skills and enjoy a good chat. You'll need to be able to show your friend respect, patience, empathy and understanding.

We’d also expect you to:

- Make time for a call or visit each week
- Commit to volunteering with us for a minimum of one year
- Agree to our volunteer terms and conditions
- Be kind and respectful to your new friend
- Let us know if you or your friend need any support

If you are interested, contact kalpana@dgmefm.org.uk for an enrolment form.



Do you know that awesome feeling when you get into bed, fall right asleep, stay asleep all night and wake up feeling refreshed and ready to take on the day?

Yeah, me neither!

Descriptions: a patient-led description of ME composed from the words of people with ME (reproduced from www.actionforme.org.uk)

In late 2021, Action for ME supported Alec Finlay, an internationally recognised artist and poet, to craft an online survey that enabled people to describe their experiences of life with M.E. Using people's words from their responses to the survey questions, Alec created a "found poem" that powerfully describes living with M.E. The poem is now available to download, buy and listen to.

Alec felt this work could put a light on the hidden, invisible nature of the condition along with the harmful impact of being disbelieved on people's health and ability to live.

Descriptions was launched at the Scottish Poetry Library in June 2022. Chief Executive Sonya Chowdhury joined Alec Finaly at the event to answer questions about the collaboration and inspiration behind the poem. The event illuminated the impact of this neglected illness on people's lives and the broader story of living with a chronic invisible illness like M.E..

The poem is now available to download, buy and listen to here: https://www.actionforme.org.uk/get-information/what-is-me/descriptions/

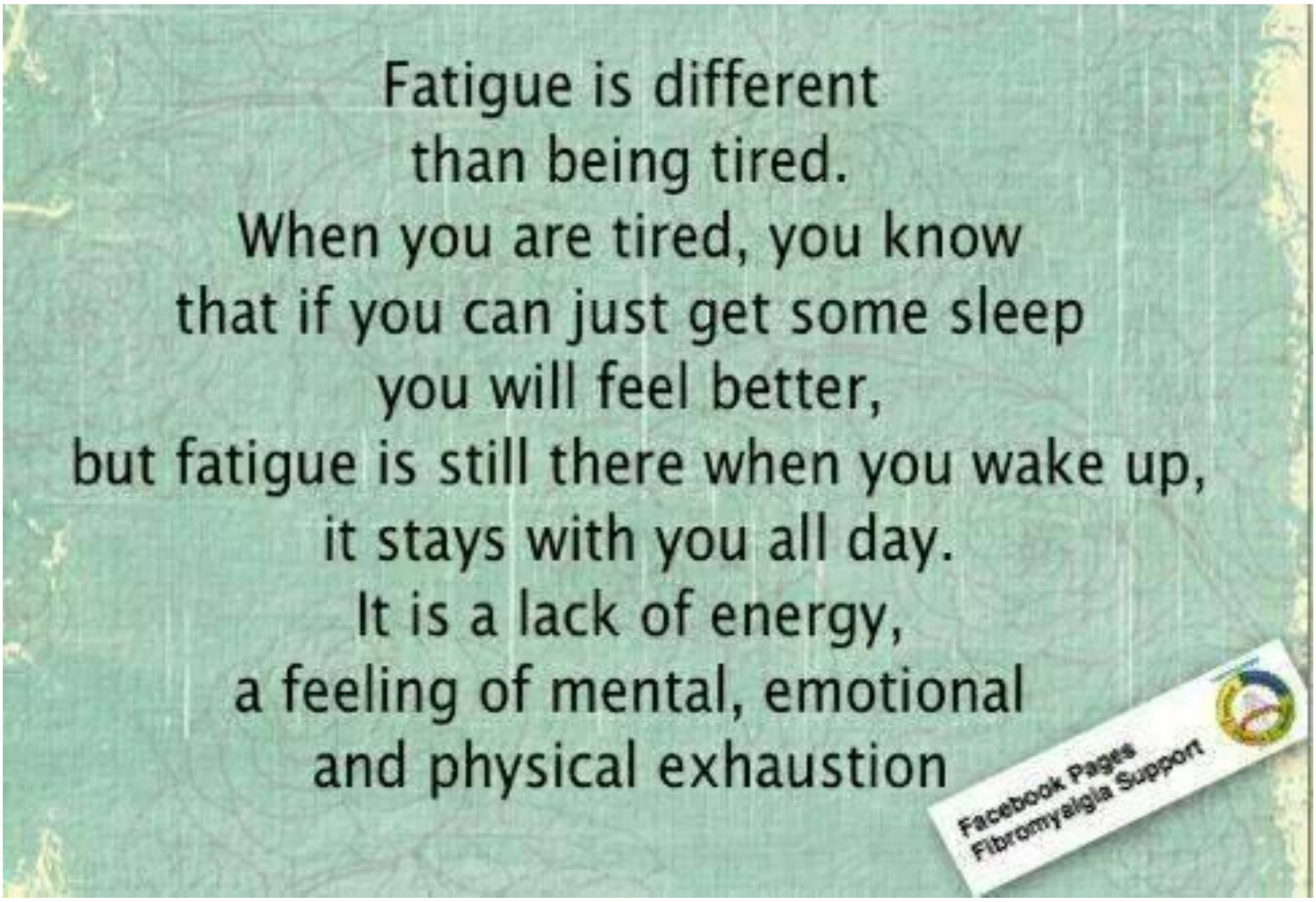
Excerpts follow:

"if I could go back in time then I'd say STOP EVERYTHING,
rest when you need to,
learn your limits, stop trying to keep your old life going,
learn to rest, rest, rest, complete rest,
stop trying to be the 'you' that you once knew yourself to be,
stop, rest, pace,
stop trying to get back to your old life,
rest, give your body a chance to recover,
stop looking for answers,
stop and rest!
stop fooling yourself that you will get better,
rest, do nothing but rest, it's that simple,
stop trying to push through,
don't fight the illness, it's OK to rest, just rest, rest, rest,
do the minimum energy allows,
rest, nothing is more important,
listen to yourself not others,
if you need to rest then rest,
stop saying yes to everything,
rest in a quiet room, give your body what it needs,
stop trying to please other people,
rest more, trust your body,
stop your perfectionist ways,
remember resting is not doing nothing,
stop every single thing you can, stop trying to do anything at all,
take time to rest or you'll make yourself worse,
let it all go and you're more likely to get it all back,
just stop, stop and rest, give in to it, and completely rest,
believe yourself, what you're feeling is real,
you need to rest, rest completely, total rest,
stop running from the pain,
resting now really is your best chance,

be kind to yourself, know that you didn't bring this on yourself,
rest, rest, rest, all I can do is rest,
ride the fear that you've overdone things
and sent yourself back down the snake,
rest!!!! as much as you possibly can,
don't try to push through like the doctors advise,
if you don't rest now it's much less likely you will recover,
you are more ill than you can comprehend,
allow yourself to rest in a dark quiet room
stop seeing the whole staircase, just do one step at a time,
your body told you to rest and it knew best,
go to bed, do nothing but sleep,
rest more than you ever thought possible,
stay there for at least 2 months,
please rest! and don't feel guilty for doing so,
take comfort in doing nothing and stillness,
take two years out and rest,
take time off work, you crazy woman!
be gentle with yourself, rest,
halve everything and then halve it again,
there is no alternative but rest, rest, rest, and more rest!
this is your life now, try and accept it and get support,
rest after everything you do,
slow down, it's OK to be a bear in wintertime,
rest, even when you feel well".

"you are not mad
you are not alone
you are not lazy
you are not the only one
you are not a failure
you don't have to prove anything
you are not pathetic
you are still you
you're not just a lazy cow
you know your own body
you are invisible
you are still enough
you don't look sick
you are braver than you know
you are sick
you shouldn't have to face this
and I'm so sorry that you are
you are strong!
you can't be there for friends
you will have the odd good days
and often you can't cope with friends
you will eventually get through it
being there for you
you will live again!"

Alec Finlay, Descriptions, 2022



Fatigue is different
than being tired.
When you are tired, you know
that if you can just get some sleep
you will feel better,
but fatigue is still there when you wake up,
it stays with you all day.
It is a lack of energy,
a feeling of mental, emotional
and physical exhaustion

Member contributions are very valued.
Thank you to everyone who has contributed to this edition.
If there's something you'd like to see in the next newsletter, or you feel able to write something for us, please do so and send to:
admin@dgmefm.org.uk

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