

June 2023

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Hello again everyone, I hope that you have been enjoying this spell of good weather. I know I have found my gardening mojo, in small sessions of activity and longer sessions of planning and basking in the sunshine. Last year I didn't do as much in my garden, the impetus just wasn't there, but I was also away quite a few times during the summer. This year there are major changes afoot. Firstly, due to an early visit to a garden centre, the inspiration was quite startling to be honest. So new plants for the pots and a bit of a rearrange of existing pots. Inevitably there are a few casualties from our very cold winter, but they just gave way to fresh ideas. I have a no dig policy, and I've adhered to 'no mow may' as well. Secondly, I have been offered a shed by neighbours who are moving house in the summer. I inherited a wonky shed with the garden, when I moved in here 10 years ago. The shed is a bit wonkier and definitely rotten in places, so a new shed is an absolute godsend. Today a friend with a chainsaw came to cut down a rather lacklustre apple tree, and an ash which was affected by the ubiquitous die back. Small steps, and the job will be done, but I am definitely not overdoing it.

Having friends, or family who can step in to help with jobs that I can no longer tackle (to be fair I would never tackle anything with a chainsaw) is such a joy. But don't you find it hard to ask for help when all your life you have been a capable human being? ME/CFS, FM, Long covid, all change our ability to carry out even the most mundane of tasks. It has taken me a long time to ask for help before even trying. I used to try, try again, then try... and make a mess of things and then ask for an even bigger favour of friends to not only complete the task but sort out the mess I had made too. It's a blooming long learning curve this chronic illness journey.

This leads me rather nicely to a request for help with the Network. As you have probably seen on the Facebook Groups and on the website, we are looking for more trustees. We have five stalwart folk who have kept the charity afloat over the past two years. Although we are only a small organisation in the grander scheme of things, the more folk we have on the Board the less the workload. As a SCIO we can have up to 12 members on the board, so there is scope for a bit of expansion. There are a few rules and regulations to adhere to, and some forms to fill out, but once that has been covered, we have Board meetings 4 times per year via zoom, along with our AGM which is a face-to-face event. If anyone would like more information about becoming a trustee, please email either myself eml@dgmefm.org.uk or Eppie at eppie@dgmefm.org.uk

The Edinburgh ME Self-Help Group (edmesh) have been in touch with news that they are having to disband. This is rather sad, and they have tried their best to carry on, however they just do not have any members stepping forward to become trustees. We will receive their remaining finances after their group is officially wound up. Paul, our Treasurer, has been in contact with them regarding this transaction.

I'm not a failure for doing less. My *capacity* has just changed. My *values* have changed. My *needs* have changed.

And I'm *allowed* to be different than who I was before. I'm allowed to want something different. I'm allowed to honor my own natural rhythm - even if others are doing more. Even if I have less on my plate. I'm allowed to rest and give my heart and time and energy to different things.

| DANIELL KOEPKE

Representatives from the Edinburgh group are attending our June meeting at Turning Point Scotland, where actual assets will be passed over to us. As this newsletter goes to print, we are not sure what the physical assets are, but will let everyone know in due course.

During the summer months we will have the usual monthly hybrid meeting, along with pop up meetings in different areas of the region. The last Crafty Friday Zoom get together for this session will be 16th June, at the usual time of 11.30am.

I hope that you can all enjoy some summer sun, maybe even a holiday to foreign climes. Whatever you get up to, take it easy, pace yourselves, and have some fun.

We are always here for help, advice, a bit of a chat, or even if you just need a rant, but for now I'll say...

Bye for now, Eileen x

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

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

Pop-Up Meet-Ups

We're excited to have pop-ups coming up in Lockerbie and Annan over the summer months.

Thanks to funding from the Communities Mental Health and Wellbeing Fund, we are able to offer a soup and sandwich meal free of charge at our pop-up meet-ups. Members will need to pay for their own drinks.

Check out the website and Facebook page for more info on dates / locations over the coming weeks.

Alternatively, give us a call on: 07557 536 110 to find out where we'll be meeting and when.

WHAT IT FEELS LIKE WHEN
A doctor dismisses my pain

Invisible
(I wish you could feel what I feel)

Betrayed
(I'm supposed to be able to trust you)

Am I actually crazy?
(Are they right? Is it really all in my head?)

Hopeless
(I'll never find someone who hears me)

HealthCentral

Test Stop Rest Pace

Reproduced from Fibromyalgia Action UK newsletter

TEST	STOP	REST	PACE
Trial	Sit Still	Relaxation	Peacefulness
Energy	Think	Evaluate	Acceptance
Scrutinise	Observe	Support	Comfort
Trust	Plan	Time out	Empathy

TEST

Trial, test out different medications, holistic approaches, and find out what works for you, what will help you maintain your wellbeing baseline.

Energy experiment with different activities to help you understand what your energy wellbeing baseline triggers are. Journal your findings.

Scrutinise your symptoms response time. It can take up to 72 hours for consequences of an activity to affect your body, physically, mentally and emotionally.

Trust in your body, it will teach you if you're willing to acknowledge and understand what it is telling you. If it is telling you to STOP-REST-PACE then be advised, STOP-REST-PACE.

STOP

Stillness, give yourself the opportunity to sit-still and be in the now moment. Think, about what your needs are in terms of; TEST - STOP - REST - PACE.

Observe, your lifestyle, consider adjusting one activity at a time.

Plan, learn to know thy 'new' self, strategize your TEST -STOP - REST - PACE.

REST

Relaxation, make time for activities that relax you to minimise your symptoms and flare-ups.

Evaluation, regularly check out any changes in your symptoms/flare-ups due to activities and lifestyle commitments.

Support, it is not a defeat to ask others for help, allow yourself assistance.

Timeout, give yourself permission for 'timeout' from life stresses and activities.

PACE

Peacefulness, create yourself 10 minutes of 'quite time' a day, read, sit with Nature, chill out.

Acceptance, work towards accepting your Fibromyalgia / M.E, Journal negative issues that arise for you, keep daily gratitude pages or jar, and positive affirmation pages or jar

Comfort, we all need a little comforting, ask someone for a hug, give yourself a nurturing hug, cultivate into your life things that comforts you.

Empathy, no one knows you better than you know yourself, offer yourself kindness, compassion and empathy in a creative way that works for you, or in a way, you would a family member or friend.

Wellbeing Baseline

Decades before I recognised,
What my internal world disguised.
My body rendered me bedridden,
One of millions missing, hidden.
FME left me slumbered in my bed,
Moreover, miserable inside my head.
Body, mind, emotions and soul,
Disgruntled in my living hellhole.
I had plans, now that bear no fruit,
Body, mind, soul became unfailingly mute.
Swathes of pain, fatigue and exhaustion,
Caused internal hypersensitive distortion.
I could not be, betrayed like this,
Bedridden, confined and dismissed.
I had to deliberate and find a way,
To create a wellbeing toolkit array.
I put a stop on catastrophizing,
Used, education and understanding.

With my transferable skills, creative I became,
Finding my wellbeing baseline became my game.
My internal observer, I become,
Awareness developed a living flame.
I found gratitude in the simplest thing,
Summer. Autumn. Winter. Spring.
As I began to learn to self-manage,
Over time, I found my new self-image.
Armed and balanced with a wellbeing baseline,
Out in my local community I began to shine.
I connected with other sufferers,
We journeyed as FME discoverers.
Contextualising our Fibromyalgia and M.E,
Trusting in each others understanding, you see.
Our mantra, 'Test-Stop-Rest-Pace,'
This is our definitive baseline grace.
For us to self-manage our wellbeing best,
We all need regular 'guilt free' Rest-Rest-Rest!

Shass Blake 04.03.2023

Fibromyalgia ME/CFS sufferer

Reproduced from Fibromyalgia Action UK newsletter

Craft and Wellbeing Workshops

We're now half-way through our most recent craft and wellbeing project, which was funded for two-years by the Scottish Government's Community Mental Health and Wellbeing Fund.

In the last year, we have hosted workshops on 11 different topics:

- Interactive cards
- Yoga
- Mindfulness
- Storytelling
- Calligraphy
- Pain Management
- Sewing
- Wreath Making
- CreativiTEA
- Tai Chi
- Stained Glass Making

46 people have taken part so far:

- 95% of participants said the workshop left them feeling happier
- 87% of participants said the workshop improved their skills
- 88% of participants said the workshop improved their confidence
- 83% of participants said the workshop helped them to feel less isolated



"I love these workshops and because my mobility is poor it's a good opportunity to interact with new people and gives me something interesting to enjoy."



"I have been off sick for months and feel very isolated and like I'm missing out on the fun bits of life. This really boosted my mood, self esteem and I felt like going for a walk afterwards because I felt much better."

We are in the process of identifying workshops for the coming year and we would love to hear your thoughts. If you would like to suggest a topic, please email: eppie@dgmefm.org.uk

Befriending Project

Hi everyone 😊 I hope you are all well and enjoying the sunshine and lighter nights.

I thought I would let you know how we are getting along with the befriending project. I am excited to let you know that we are going to start training our new befriending volunteers in the next month or so (it's still not too late to volunteer!)

If you're interested in using the befriending service, for yourself or someone you know, please get in touch with me at kalpana@dgmefm.org.uk or on 07761048514.



I look forward to hearing from you soon.

Kalpana

Enabling older and disabled people to stay in their own homes

Welcome to our first Care and Repair, D&G Newsletter

What a year it's been. Care and Repair, Dumfries and Galloway, went through the Dumfries and Galloway Council's procurement process and as of 1 July 2022 is now managed by Care and Repair in Lanarkshire. The existing staff transferred via TUPE from Loreburn Housing Association to Care and Repair Lanarkshire. We have relocated to an office at Eskdale House based on the Crichton Estate, Dumfries.

"Care and Repair staff were very helpful and explained everything thoroughly. We have both used the shower, it has made a huge difference to my wife's ability and confidence to have a shower, everything about it is perfect. The contractor was very professional and extremely tidy."

The team is managed locally by Jane Glanville, who has been leading the team since 2018. Emma Carnochan, Alison Lees and Laura Craig are the Officers who are out and about in the community dealing with the referrals. They are supported by Linda Munro and Allana Hamilton who carry out the administration and finance tasks. We are a small but friendly and helpful team who are all passionate about the service and delivering good outcomes for our clients. We are supported by Jamie Burgess the Manager of the Care and Repair Lanarkshire Service.

At Care and Repair we aim to help people to remain living at home independently and safely, with confidence and dignity, in their own community.

We provide support and advice to people over the age of 60 and disabled people of any age, who are home owners or tenants of private landlords throughout Dumfries and Galloway. The Care and Repair team offers free, confidential, independent advice to clients, assisting them to carry out disabled adaptations to their homes. We support clients from the start of a project through to completion with grant applications, work specifications, contractor tenders and project management.

The service receives funding to provide grants for adaptations to allow people to continue to live safely in their own homes. In order to receive a grant one must be referred to Care and Repair from the Occupational Therapy Team, Social Work Services, Dumfries and Galloway Health and Social Care Partnership.

The typical works carried out are stairlifts, through the floor lifts, external step lifts, wet floor showers, ramps and hoists. Where we can, we recommend local contractors, which contributes to investing and supporting the local economy.

All clients receive 80% grant funding, however, those in receipt of qualifying benefits get 100% grant funding. Please note that the cost of work includes grant funds allocated and client contribution, where appropriate.

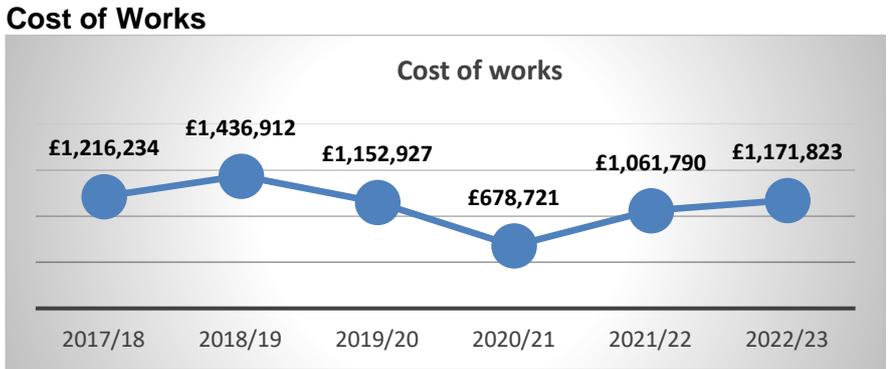
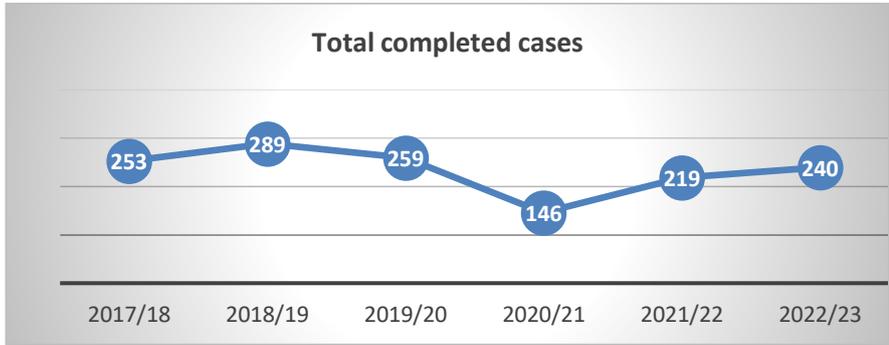
We work hard to ensure that we achieve value for money and achieve the maximum amount of work that we can with the funding available. This is a challenge in the face of increasing contractor wages and material costs.

**If you would like to speak to anyone in the Care and Repair team you can call us on
01387 217744 (Monday–Friday 9am-5pm) or
e-mail us on enquiries@careandrepair-dg.co.uk**

Completed Cases

"I would like to add my thanks. You have always been available and willing to give advice and help to us throughout. I am truly grateful for helping make Mums life more independent."

“Officer explained everything great and straight forward. Very happy with the work carried out and the time it took.



I would like to say thank you, and it has made a big difference to my Dad”.

Before external steplift installed



After



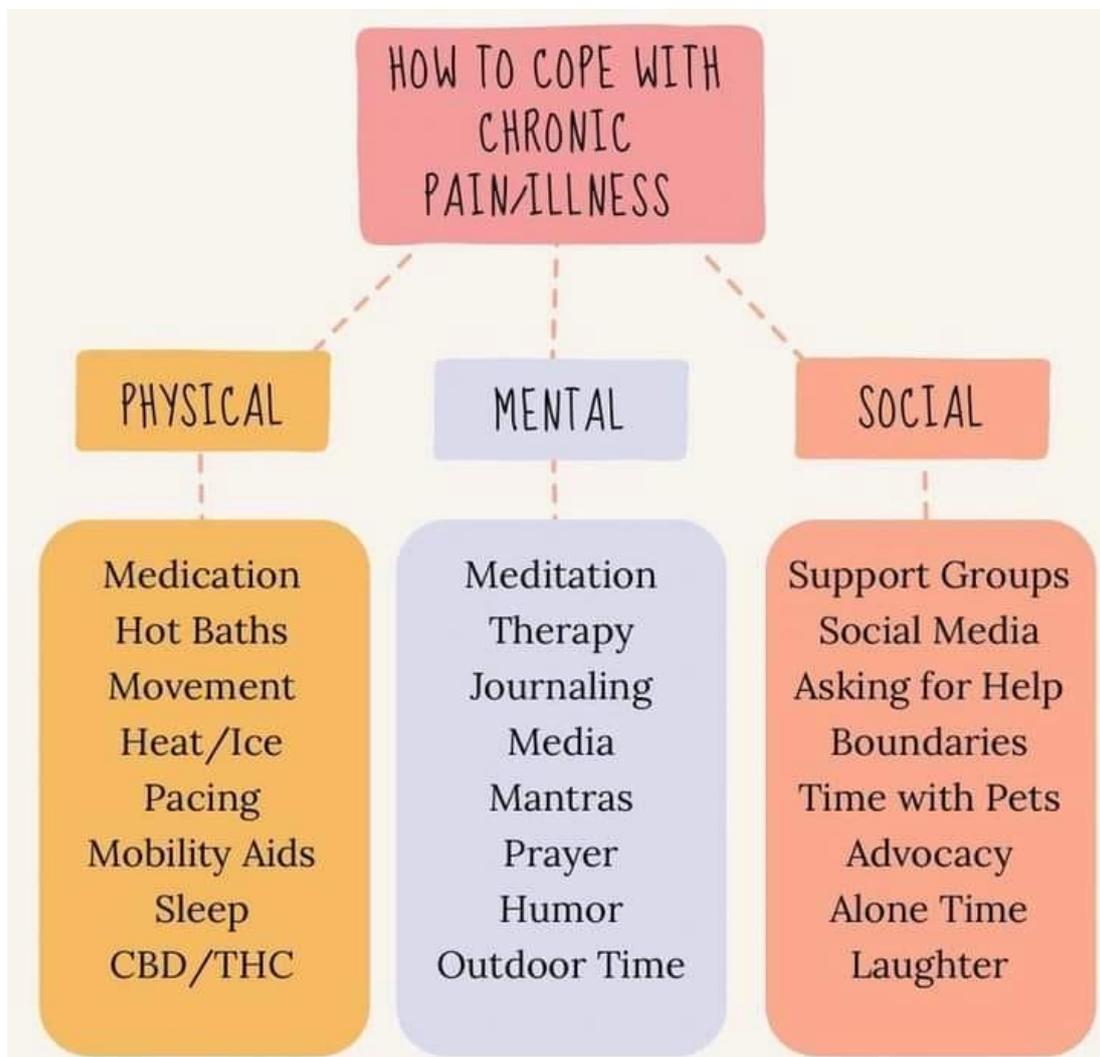
Before wet floor shower installed



After



“Thank you so very much for all your help it really has made a huge difference to both of us especially for the future. Contractors were efficient and professional.”



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



Phone or WhatsApp: 07557 536110
 Website: www.dgmefm.org.uk
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