

September 2021

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Welcome all,

Again, I need to start with an apology. The committee have been very busy with various projects and developments that the newsletter has suffered once again. This year continues to be a bad one for energy and pain too. Something had to give, and it was the newsletter. I know how much it means to those who aren't online, so I can only say how sorry I am for that.

There've been many developments since I last wrote this introduction in February. As I write this, there's a huge bomb gone off in the ME world with the cancellation of the publication of the new NICE Guidelines on ME/CFS. The draft published last November was surprisingly good as far as we were concerned – too good for us, and bad for those who've built a career on imposing Graded Exercise Therapy and CBT (as a cure rather than as a coping mechanism) that the fuss created caused the shelving of the publication. More about that later in the newsletter, with developments coming in as we go to print.

We've had the publication of the Scottish needs assessment study of ME – this was hugely overshadowed by Covid. It seems an age ago, but our last meeting at the Midsteeple, before lockdown, was contributing to this through a consultation. It came out with some useful suggestions and showed how lacking current care is. We intend to follow up to try to prevent it from being shoved to the back of the Government's and NHS's filing cabinet never to be acted on or referred to.

In the Network we've had success with funding applications, allowing us to progress some projects and to safeguard what we do currently. It also means that we won't need to rely on our members to the same extent. However, your support, if you can afford it, would be gratefully received. We still need unrestricted funds to pay for the costs of fundraising (thereby making any donation work much harder) and it also helps to show our funders how valued we are.

Our Craft Project wound up in May and it was a huge success. We've secured funding to run it again and are looking forward to re-starting it over the darkest days of this winter.

We've also been dealing with the covid vaccinations – getting access to them for people with ME in the region, and then dealing with the relapses they often triggered. As the country begins to return to the new normal we are having to adapt to suit, and protect ourselves as best we can.

Craig Woods

**Notice of
AGM
Thursday 7th
October
2pm via Zoom**

Notice of Annual General Meeting (AGM) 2021

We will hold our AGM on Thursday, 7th October at 2pm online by Zoom. See page 2 or our Facebook Group, for the Zoom ID and passcode. Alternatively request by phone or email.

[Please get in touch if you would like copies of our Annual Reports beforehand.](#)

Contact us:

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Registered Charity No. SC030641



If you, or someone you know, may be interested in joining the Committee, whether existing or new member, friend, partner, or family member, please let us know before the AGM if possible. We want to strengthen the capacity of our committee and also include supporters who are themselves well, but can appreciate our lived experience of ME/CFS and Fibromyalgia.

At this year's AGM, one of the matters we will be voting on relates to whether or not we would like to change our status to become a Scottish Charitable Incorporated Organisation (SCIO). Now that we have been successful in securing some larger pots of grant funding, it may well be the natural next step for the organisation as it would provide a greater degree of security for both our Trustees and any staff we take on. Please join us at the meeting to hear the discussion and share any thoughts you might have.

Crichton Central Meet-Up

We had hoped to meet in person shortly but will postpone again until the levels of Covid in the region come down from their current record highs. When we do meet, we intend the venue for a social meet-up to be Crichton Central. We chose Crichton Central, on the beautiful Crichton Campus in Dumfries, because of its covered terrace. The café has a deli bar with sandwiches, pizzas, jacket potatoes and all-day brunch options.

When we release dates we will notify you on Facebook, our website and by email. Please let us know if you think you might like to come along, as we'll need to reserve a suitably sized table.



Online Zoom Meetings Every second Thursday 2pm – 3pm

We have yet to set topics for our upcoming meetings. We intend to have meetings on: Long Covid (with sufferers telling us about their experience); the controversy around the NICE Guidelines on ME (hopefully with Dr Purdie); there will also be social meetings and a get-to-know meeting with a Network member. If you have any suggestions for meeting topics, please let us know via the Facebook Group, phone or e-mail.

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 5695 7034, Passcode: 2021

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

NICE Guidelines Revision in "Pause" Shock

By Stuart Brown

After years of deliberation and a four-month postponement, Wednesday 18th August 2021 was expected to be a day of joy for ME/CFS patients. This was the day when, finally, the much-anticipated review of the NICE guidelines for ME/CFS were to be published.

NICE is a slightly tortured acronym for National Institute for Health and Care Excellence – it's a body that issues official guidance on the appropriate treatment and care of patients in England & Wales, but many other places, not least Scotland, follow its lead closely.

A draft of the new NICE guidelines, published last November, caused great excitement as it contained dramatic changes from the previous version in 2007.

- CBT as a cure was debunked – it should no longer be offered as a treatment, only as a coping therapy.
- GET was found *not* to give benefit, and in some cases caused harm. NICE now cautioned against its use.
- Over a hundred studies of GET and CBT – all based on the so-called BPS or "Bio-Psycho-Social" hypothesis of the illness – were graded as low or very low quality. After decades of campaigning, the much vaunted "evidence base" for those therapies had crumbled under NICE's expert scrutiny. ME/CFS was no longer "all in the mind" – now perhaps a new dawn, with a focus on biomedical research, was finally beckoning.

Despite a months-long delay from the original publication date in April, and the drama of resignations in the weeks running up to publication day, the indications were that these core revisions were to be included in the final version of the new guidelines. And so indeed they were, according to those privy to the final draft in recent days.

But then a bombshell – *"It has become apparent that a number of professional groups are unwilling to support the guidelines"*, said a statement issued by NICE on Tuesday night. *"In order to have the desired impact, the recommendations must be supported by those who will implement them and NICE will now explore if this support can be achieved"*.

"... those who will implement them..." – the shrinks, the physiotherapists, the peddlers of CBT and GET. Having lost the argument with NICE, were now simply refusing to recognise the new revised guidelines. It's a mutiny against their own professional body.

"NICE has today taken the decision to pause publication of its updated guideline on the diagnosis and management of ME/CFS", said NICE in their statement, warning ominously –

"Unless the recommendations in the guideline are supported and implemented by professionals and the NHS, people with ME/CFS may not get the care and help they need".



The ME Association seemed blindsided by the announcement: *"We are shocked and hugely disappointed to hear that the long-awaited NICE guidelines have been unexpectedly delayed at the last minute. The new NICE guidelines bring clinical practice up to date with current scientific knowledge regarding ME"*, adding –

"Delays will hold-off still further the desperately needed improvements to patient care."

Nina Muirhead (seen right), head of medical education at Doctors for ME said: *"Doctors are in desperate need of improved support in how to care for patients, delaying that prolongs unscientific approaches which have no place in our medical community"*.



And ME Action UK said:

"At a time when NICE needs to show strength, and to back their own independent processes, they have instead shown a depressing level of weakness. They are

capitulating to the vested interests of those who support graded exercise therapy, instead of standing up for the thousands of people being harmed”.

As this newsletter went to press there was no information from NICE as to how long their “pause” may last or how it might end.

The fight goes on.

Countdown to Publication

September 2017:

NICE decides that a full update is necessary for its guidelines on the diagnosis and management of ME/CFS. There hasn't been a full update since 2007.

January 2018:

The new review of the NICE guidelines commences.

10th November 2020:

The draft of the new guidelines is published. They pan nearly all CBT and GET evidence as being “low” or “very low” quality. It says there is a “lack of evidence for the effectiveness of these interventions”.

21st April 2021:

The original publication date for the new guidelines, but it is pushed back to August “because of the large number of comments received during the consultation” on the November draft. NICE say the draft attracted 4,000 responses.

2nd August 2021:

The ME Association's **Dr Charles Shepherd** is forced to step down from the NICE guideline committee after a complaint from someone monitoring the Association's social media. While answering a question from a concerned patient, Shepherd had initially appeared to describe the contents of the yet-to-be-released new guidelines, before later clarifying he was talking about the already-released November draft. His original comments were deemed a breach of committee confidentiality agreements, and prompted “discussions” about Shepherd having a conflict of interest due to other public comments he had made about CBT and GET.

There have apparently not been any discussions about other committee members having conflicts interest despite several of them having jobs that rely on the belief that CBT and GET are efficacious.

3rd August 2021:

Three further members of the NICE committee resign. The three are all providers of CBT and GET-based “care” for folk with ME/CFS.

- **Michael Beadsworth** – based at the Royal Liverpool University Hospital, and clinical lead for its ME/CFS regional service.
- **Gabrielle Murphy** – clinical lead of the “fatigue service” at the Royal Free London NHS Foundation Trust.
- **Joanne Bond-Kendall** – senior physiotherapist at the specialist paediatric ME/CFS service at the Royal United Hospitals Bath NHS Trust.

An article in the British Medical Journal, which frequently defends CBT and GET-based therapies for ME, suggests the three are protesting the process by which the NICE review committee has

come to its conclusions. A key dislike is “an unusually high number of patient representatives” on the committee, leading they say to more weight than usual being placed on patient views rather than published evidence, in particular around the issue of the potential harms of exercise therapy. Only five of the 21 committee members were patient representatives; but that’s up from the usual two, they say.

17th August 2021:

NICE announces it is “pausing” the planned 18th August publication of its new guidelines on the diagnosis and management of ME/CFS, causing outrage among ME patient groups and campaigners who have been waiting years for this much-needed modernisation of the guidelines.

Stop Press - NICE Press release 27th August

Following the pause to the publication of the guideline NICE has today, 27 August 2021, announced that it is to hold a roundtable event to better understand the issues raised and determine how it can gain support for the guideline to ensure effective implementation.

The meeting, which will be held in September 2021, will have an independent chair and will include representatives from patient organisations and charities, relevant professional societies and from NHS England and NHS Improvement, NICE and the guideline committee.

Paul Chrisp, director for the Centre for Guidelines at NICE, said: “Our aim throughout this process has been to use the best available evidence as well as the lived experience of people with ME/CFS to address and resolve the continuing debate about the best approach to treating people living with this debilitating condition. We remain optimistic that we can reach a way forward to publish a guideline that will have the support of people living with ME/CFS, the people who care for them and the professionals who treat them.”

My Experience Using ActiPatch, by Diane Bond

I first came across this device as a trial my Practice Nurse was doing in Lincolnshire. She had fibromyalgia and looked for a way to “return to normal”. I had a bit of a wobble and said to my GP I was not prepared to accept Opioid drugs as a long-term solution to ME/Fibro. She eventually sent me to this nurse...I thank the day I got stropky.

I used to get headaches that would put me in bed for 2/3 days at a time, vomiting etc. Now, I have only had that a few times since using the device and lasts a day or so. Muscle spasms used to wake me on a nightly basis, like someone thumping my bottom, thigh and back mainly but all muscles. It used to do circuits around my body, limbs and face. During the day it meant I temporarily couldn't use muscles, I'd get cramp, locked hands, wouldn't open to use them. I still get spasms, less in severity, can usually get on with my day, they are much shorter in duration. Still get annoyed with them at night but again less obvious. I can usually settle, toss and turn but get some sleep unlike before the device when I'd get woken and in pain.

I still get pain, try distraction, move about house a bit, a warm drink, ten minutes quiet time eyes closed. If it continues or gets worse, I give in and have paracetamol. That's got to be sooo much better than Opioids. I have only used co-codamol for three days in past 18 months. My muscles used to be so stiff I couldn't get out of bed, shower, dress without assistance. I still need help at times but given an hour and a half...I can pretty much manage most days. I was convinced at my worst that I wasn't far from being in a wheelchair. Point proven when at the start of lockdown I missed a month, couldn't get them. I ended up in bed, on the sofa, crawling up stairs. All the symptoms returned, pain increased, couldn't cope.

This is no miracle cure, nor is it supposed to be. It does allow me free-er movement, less pain/ manageable much more at least.... and it can be used LONG TERM unlike most medications. I wear it 24/7, except in the

shower, can't bathe with it on. Only side effect I had was a reaction to the tape you put it on with. I'm allergic to sticky stuff. That has now been changed since being available in the UK. Much safer and easier to put on....unless it's on your back. I wear one at the top and one at the bottom of my spine. I also use Biofreeze Gel occasionally.

What is ActiPatch?

The manufacturer claims that the product provides advanced long-lasting chronic pain relief using Electromagnetic Pulse Therapy and works great for back pain, knee pain, muscle & joint pain, arthritis, sciatica, fibromyalgia, strains, sprains and more.

ActiPatch is drug and ingredient-free so is safe for continuous use and can be used while taking any other medication.

Unlike a TENS machine, you will not feel heat or vibration. ActiPatch is completely sensation free. TENS machines are designed to provide pain relief by blocking pain signals, with treatments typically lasting 20-30 minutes. ActiPatch was designed to reduce pain and inflammation and thereby promote healing. Unlike a TENS machine, ActiPatch can be used continuously and for long periods.

And unlike a bulky TENS machine which requires gel and electrodes on the skin, ActiPatch is a lightweight solution that is attached with adhesive or inserted in a wrap/bandage.

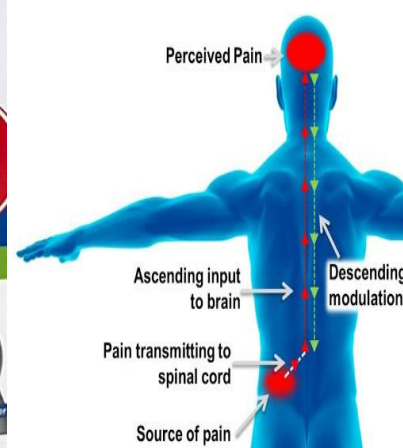
From the manufacturer:

Chronic pain results from central sensitization, which causes the nervous system to develop a persistent state of high reactivity. This serves to amplify and maintain the pain even after the initial injury has healed. Therefore, chronic pain is often poorly correlated to the degree of peripheral tissue injury.

ActiPatch's electromagnetic signal pulses 1,000 times per second to stimulate neuromodulation of the afferent nerves to dampen the brain's perception of pain.

My local GP prescribes ActiPatch for me. Because Scotland won't supply electronic devices on prescription I have to have it fulfilled by an internet company and pay the standard English prescription fee of £9.35 for it to be delivered. I use chemist-4-u.com. It is also available to purchase without a prescription.

Diane Bond



Fibromyalgia Research News: Elevated Intramuscular Pressure Found

Adapted from an article by Cort Johnson on www.HealthRising.org.

A recent study of 100 Fibromyalgia patients (with 30 healthy controls) by Robert S. Katz, et al, published in The Journal of Rheumatology shows that intramuscular pressure in patients with fibromyalgia is much higher than normal.

Many muscle studies have been done over time yet when it comes to explaining FM they are hardly mentioned. Instead it's the central sensitization theory that holds sway.

The painful, tight and/or constricted muscles were a defining characteristic of the disease. The term Fibromyalgia came from the Latin word “fibro” (fibrosis tissue), and the Greek terms for “myo” (muscle) and “algia” (pain).

The researchers must have had an idea that they would find muscles under high pressure in FM. Stating that muscle pressure was “extremely elevated” in the FM patients, they reported that it was **three times higher**... The intramuscular pressures were so different in the FM patients, the authors suggested they might be a diagnostic biomarker.

So what does high pressure do to a muscle? The authors reported that it can compress the capillaries – the smallest blood vessels – possibly obstructing blood flows to the muscles – reducing the delivery of oxygen to them – causing the muscles to rely more on anaerobic energy metabolism, resulting in fatigue and pain.

A previous study noted that hyperbaric oxygen therapy, as used by divers recovering from ‘the bends’ – which now has a couple of positive studies under its belt – could be helpful. It was also noted that magnesium – a supplement commonly used in FM and chronic fatigue syndrome (ME/CFS) – can help to dilate the blood vessels by supporting nitric oxide (NO) release. (NO is produced by the blood vessels to dilate them.)

Many of our members find benefit from using magnesium sprays or getting their magnesium through taking Epsom salt baths.

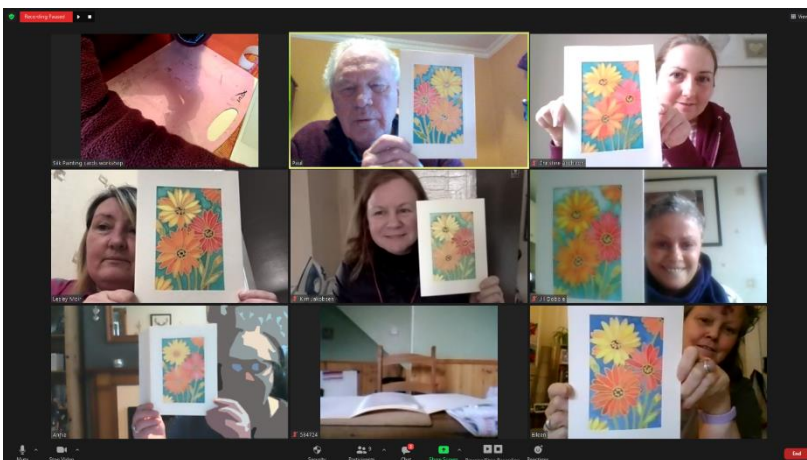


High muscle pressure could be squeezing the capillaries – reducing blood flows to the muscles.

Silk Painting Card Making Workshop

This workshop, held on 3rd March as part of our crafts project, was an introduction to painting on silk, to make greeting cards. Members were sent starter packs with 5 botanical designs with backing paper, paints, cards and most of the equipment needed, together with introductory instructions. As with other workshops, places were limited to seven but, as it was over-subscribed, could be offered again this Winter.

Members were shown how to mix the three primary colours in the kit, plus the black and white, to create the colours and shades they wanted. We worked together on one of the designs through to mounting it in an aperture card. The session was recorded and sent to participants for reference.



For me it was a steep learning curve to find out how to work with two cameras (one to show my workspace) and manage Zoom controls, at the same time as demonstrating and paying attention to everyone! Everyone enjoyed it though and more cards were shown off in later days in our Facebook group.

Some of the feedback:

“I thoroughly enjoyed it and look forward to doing more silk paintings. Was lovely to meet you all, as this was my first ever zoom meeting!”

“This silk painting is so therapeutic. The workshop was amazing. If anyone is still undecided about joining any of the Networks free Craft Workshops, my advice is to go for it.”

Paul

Fatigue And M.E.

I have a worry on my mind
That spins my head around
It causes grief, it's beyond belief
And an answer must be found

It's about a word that's used a lot
A word filled with intrigue
Not beat, not weary, not tired or wired
But that bleedin' word fatigue !

It's one to use after a busy day
Round the shops, or out at play
It's what will fade with a bit of rest
But to explain M.E. ?..... I do protest !

My trouble with this word is that
It's not my biggest pain
It's other things that clip my wings
And cause my life to wane

Light and sound is all around
And cause me endless grief
Background noise and kids with toys
Take my legs from underneath

Each bang or crash or background sound
Makes my head just spin around
To a normal soul it's just a noise
To me it's pain, an energy drain
Not something that just annoys

What we have is not fatigue
It's the body closing down
Looking to protect itself
Trying not to drown

All these things I list above
Drain the spark from all our lives
You will see us wilt, our vigour spilt
Right before your eyes.

The wheels might still be spinning
But the gears just disengage
Our circuit's fried, our system's died
We're trapped within a cage

The pain that rises, still surprises
It comes from oh so deep
There's a silent shout
As nerves cry out
And stops any thought of sleep

I lose my senses one by one
My speech and sight has gone
I fail to hear, thoughts unclear
All my nerves are torn
All resources taken flight
I'm left with just my pilot light

So I say to you, the caring few
Is that the fatigue that you go through
Is your world wrapped in a bruise
Is this a life that you would choose ?

It's time to lose that awful word
To link to M.E. is just absurd
Let's get rid of that name fatigue
Out the door, it's time to leave

Is Alzheimer's just forgetfulness
I don't think that's the case
So fatigue no more explains our plight
So let's ban it without trace

So the question left is quite sincere
Where the hell do we go from here ?
To have M.E. is bad enough
Being looked down upon is pretty tough
We need awareness of our plight
Banish this word with all our might

So as I end this hopeful plea
I feel it's just so clear to see
We have to drop the term fatigue
Let it be known by its name.....M.E. !

By Bill Clayton © 2019

Healthcare Improvement Scotland's Lived Experience of ME Report

It may seem seem a lifetime ago (February 2020), at the last Midsteeple meeting before the pandemic, The Network contributed toward this report commissioned by the Scottish Government. The report was published in May this year to very little publicity, overshadowed, as it was, by the pandemic and repercussions of it.

As well as lessons for the government and NHS on how to improve our own care, it should give warnings about what improvements are needed for those newly ill with Long-covid, so that the same mistakes are not repeated. The Network intends to push for recognition of this report and that the recommendations should be acknowledged and acted upon.

The report runs to 27 pages and is available in full at www.hisengage.scot.

The findings and recommendations are summarised by the authors below:-

Findings

This report summarises what people living with ME in Scotland told us. Some were able to describe positive experiences of diagnosis, compassionate support and ongoing care.

However, many respondents outlined a less positive experience, including what they described as:

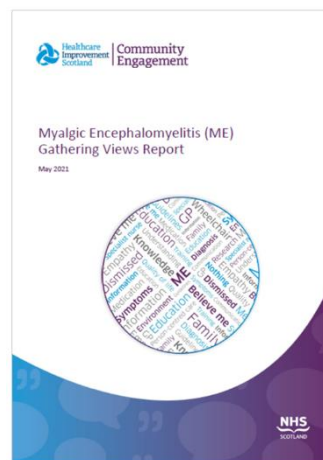
- lengthy diagnosis
- unnecessary tests
- a lack of information about the condition
- an absence of person-centred care planning and delivery
- low levels of knowledge about the condition among staff, and
- a lack of belief when they interact with services.

Many of the respondents felt isolated and reported that they were left to get on with managing their condition with limited input or support.

The responses received have been shared with colleagues in Scottish Government to help shape their work in establishing an evidence base around the care and support for patients with ME.

Recommendations

- Scottish Government to develop clinical guidance for staff to support the diagnosis and treatment of ME. This could be developed with the support from charities and third sector organisations who provide advice and support for people living with ME as well as specialist nurses and clinicians. People living with ME and their families must also be involved.
- Scottish Government to look at how to increase access to specialist services for people living with ME across Scotland. Digital and other technologies could be explored to enable this to be achieved.
- Health and social care services to ensure that people living with ME can access relevant professionals and services to enable them to have their needs met.
- Scottish Government to encourage and support further research into ME and how people live with the condition, including working with third sector organisations and charities. People with lived experience should be involved in any research.
- Scottish Government and health and social care services, working with people living with ME, to develop a person-centred holistic approach to the provision of care for people living with ME. This would include input from informal carers.



- Scottish Government should update relevant national publications where appropriate and consider how to improve access to relevant information for both clinicians and those living with ME.
- Health and social care services should work with those living with ME to ensure appropriate appointments are given. This should include the exploration of digital and other technologies to provide an appointment for people within their own home.
- Health and social care providers should consider how they ensure appropriate links with services such as mental health and befriending can be provided to those living with ME and their families.

Impact

This report has been shared with the Scottish Government and the information gathered through this exercise will be used to help inform an evidence base to support the care and needs of people living with ME, with a view to developing a national action plan.

‘Easy Access’ at Council-Run Leisure Centres

Now that council leisure centres are reopened, did you know that you can get reduced or half-price access? Ask about ‘Easy Access’ – with it a swim could cost as little as £2.60.

You will need to have a qualifying benefit or evidence of disability.

Note that booking might be required.

Contact the council’s main contact number on 0303 333 3000 and ask to be put through to your local leisure centre to enquire or book a session.



Long Covid booklet produced in association with the ME Association

The Network has jointly produced a booklet with the ME Association for people with Long Covid in the region. I’m told this is the first time the ME Association has partnered with another charity in this way.

It contains basic information for those in the early stages of the illness and signposts those with post-viral fatigue towards us. With the similarities with ME, our experience and support, particularly around post exertional malaise and pacing could make a big difference to their outcomes.

If you would like a copy of this booklet or know of somewhere that could distribute a supply of them, please get in contact.

Funding and Development work

The grants from the Robertson Trust towards our running costs and from Foundation Scotland mentioned in our February newsletter allowed us undertake the craft project between February and May, and to appoint a temporary part-time Development Officer, Senga Armstrong. She helped us promote a training module on ME/CFS for GPS, and health and social care practitioners, and in collaboration with the ME Association, publish and distribute a booklet aimed at long-covid sufferers about the management of Post-viral fatigue and PVF syndrome following coronavirus infection. Senga's contract ended at the end of May and through personal circumstances had been unable to work all the hours available. An extension to the funding period to the end of July meant we could engage a contractor to improve our website.

We've since been successful with three more funding applications thanks to work on our behalf by Grace Cardozo and Rebecca Giblin of Sleeping Giants.

- The Health and Social Care Alliance gave us a grant for a feasibility study on a possible mentoring/befriending project, and to build more solid foundations as an organisation developing a strategic plan and policy framework. Grace and Rebecca of Sleeping Giants have been commissioned for that work running into the Winter months.
- A Lottery Community Fund grant allowing us to appoint a new contractor for part-time admin and development support until July next year (Eppie Sprung), and to offer another series of craft sessions in the coming Winter months.
- An award from D&G NHS Endowment Fund covering the cost of our newsletters for the year ahead and for restarting in-person meetings.



Hello!

Hi, my name is Eppie and I am excited to be working with you all over the next few months.

I work with a number of charities and social enterprises in Dumfries and Galloway, helping them to set up and to grow. I also have a one-year-old daughter who keeps me on my toes!



I hope that by being involved with the Network, I'll be able to make life a little simpler for your Trustees by taking some of the more administrative tasks off their hands.

I have a personal connection to the work of the Network, as two of my close family members have ME. It will therefore be particularly nice to be working to support a cause very close to my heart.

I look forward to meeting some of you in person over the coming months!

Order Lateral Flow Tests Online

Many of us will be anxious about meeting up in person again for fear of how covid could worsen our illnesses, as much as for the fear of Covid-19 itself. To lessen the anxiety and risk we, and those around us, can test ourselves regularly. This could be something we do before attending our Crichton meeting, for example, to help protect those around us.

You can get regular rapid lateral flow tests even if you do not have symptoms of coronavirus (COVID-19).

Why you should get tested regularly

About 1 in 3 people with COVID-19 do not have symptoms but can still infect others.

You should do a rapid test twice a week (every 3 to 4 days) to check if you have the virus. If people test positive and self-isolate, it helps stop the virus spreading.

Even if you're vaccinated, there's still a chance you can pass COVID-19 on, so you should keep getting tested regularly.

About rapid tests

The test for people without symptoms of COVID-19 is called a rapid lateral flow test.

This usually involves rubbing a long cotton bud (swab) over your tonsils (or where they would have been) and inside your nose.

Tests give a quick result using a device similar to a pregnancy test.

You can do a rapid test at home or at a rapid lateral flow testing site.

Research shows rapid tests are 99.9% accurate. This means the chance of getting a false-positive result (where the result shows as positive but is actually negative) is extremely low.

If you test positive, you must self-isolate. Check if people you live with need to self-isolate.

Who can get regular rapid tests

Anyone who does not have symptoms can get regular rapid lateral flow tests to check for COVID-19.

How to get (free) regular rapid tests

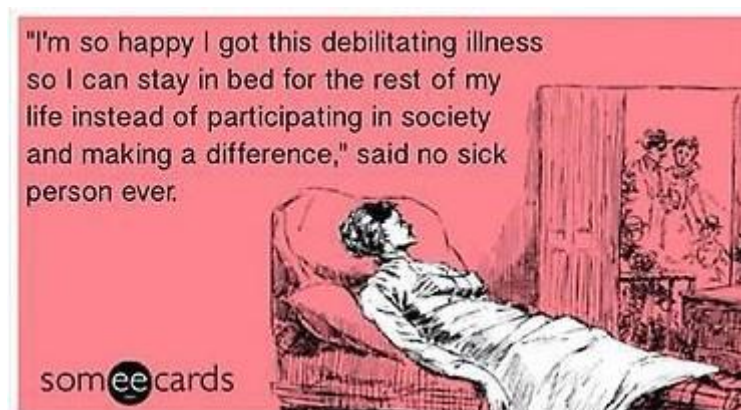
Order tests online: If you order online, you can get rapid flow test kits sent to your home.

Order here: <https://www.gov.uk/order-coronavirus-rapid-lateral-flow-tests>

OR

Collect tests from your local pharmacy. They won't be on display but will be available by asking the staff for no charge.

If you do tests at home, you'll need to report a positive result online or on the phone.



From DNA to drug development. Five success stories show the potential of DecodeME

Reproduced from Decode ME's website.

How do you find treatments for a disease like ME/CFS, where nothing is known for sure about its causes? One way scientists can now look for answers is with very large DNA studies, like DecodeME. This fairly new approach is already giving insights and pointing to treatments for a range of illnesses, including rheumatoid arthritis, type II diabetes and even severe Covid.

The clue lies in our DNA



DecodeME will use small differences in the DNA of people with ME/CFS to look for biological causes of the disease.

Tiny differences in our DNA can help pinpoint what's going wrong in our bodies. And understanding what's going wrong biologically is the starting point for finding treatments.

DNA is the master molecule of life, storing all the information needed to make and run the human body. The information is stored in DNA using chemical letters. There are only four letters, but our DNA contains a sequence of 3 billion of them, like a very long book.

Mostly, our sequence of letters is exactly the same as those of the next person. But for around a million positions in the book (fewer than one in every one thousand), the letter can differ from person to person.

Scientists then compare these DNA letter differences between people with an illness, such as ME/CFS, and healthy people. Often, they find that a few of these differences are slightly more common in people with a particular disease than those without it.

These DNA differences, perhaps only a dozen or two, are clues to what is going wrong in an illness.

Summary: 5 big DNA study successes

Big DNA studies are still relatively new and the science that drives them is developing all the time. But these five examples show the power of the approach.

1. In rheumatoid arthritis, it led to ongoing development of new drugs that aim to tackle the root of the problem.
2. It led to the discovery that several autoimmune diseases could be treated with drugs already developed for other diseases.
3. In Type II diabetes, a surprising discovery led to development work on a new drug.
4. In Alzheimer's disease, DNA research indicated that researchers should look for answers in the brain's "support cast" of cells.
5. And in Covid-19, the most devastating illness to strike the world in over 100 years, a DNA study has already provided powerful clues to scientists looking for life-saving drugs.

Looking for answers across human biology

One of the main advantages of big DNA studies is that they look across all 3 billion letters that make up the DNA book of life. This means that they are effectively scanning the whole of human biology.

This is particularly important for a disease like ME/CFS where we know so little - you don't even need to know what you're looking for.

There are no guarantees with any research study, but we hope that DecodeME will make a big difference.

First, we need to find 20,000 people to take part. If you would like to be one of them, please sign up and you can be first in line when we start recruiting in the autumn. Sign up here: www.decode.me.org.uk

Single Access Point

By Dumfries and Galloway Council

Single Access Point (SAP) is the point of contact for all new non-clinical emergency Health & Social Work Community Referrals. The team consists of Call Advisors, Senior Social Worker, Senior Care Co-Ordinator and Social Work Assistants. We also have our health colleagues who are now co-located with us (2 Health Advisors and Admin). Co-location has stream-lined our processes, reduced duplication and improved our communication.

SAP processes referrals for Social Work (both Adult and Children), Social Work Occupational Therapy, Mental Health Officer, Multi Agency Safeguarding Hub (MASH), Physiotherapy, Community Nursing, Health and Wellbeing Team, Pharmacy, Community Rehab Occupational Therapy, Podiatry, Dietetics and Speech and Language Therapy. Once all the information has been taken for the referral it is then screened by the operational staff within SAP, which may be Social Work or Health staff. This helps ensure that the referrals go to the right service at the right time.

SAP receives referrals via email and telephone. Due to the high volume of calls we have call back requests. In order to prioritise workload we have a priority framework and Red Amber Green system in place. Staff are allocated different tasks each day to avoid duplication. As SAP has evolved, the number of referrals has increased significantly since August 2020.

COVID-19 has impacted many services and SAP has experienced many changes and challenges over the last 12 months. SAP has experienced increase in demand, change in processes and staffing changes. Despite all of these challenges we have developed as a team and as a service.

If you would like to make a referral to any of the above services, then please contact SAP on 030 33 33 3001 or AccessTeam@dumgal.gov.uk. SAP operates from 9am to 5pm Monday to Friday

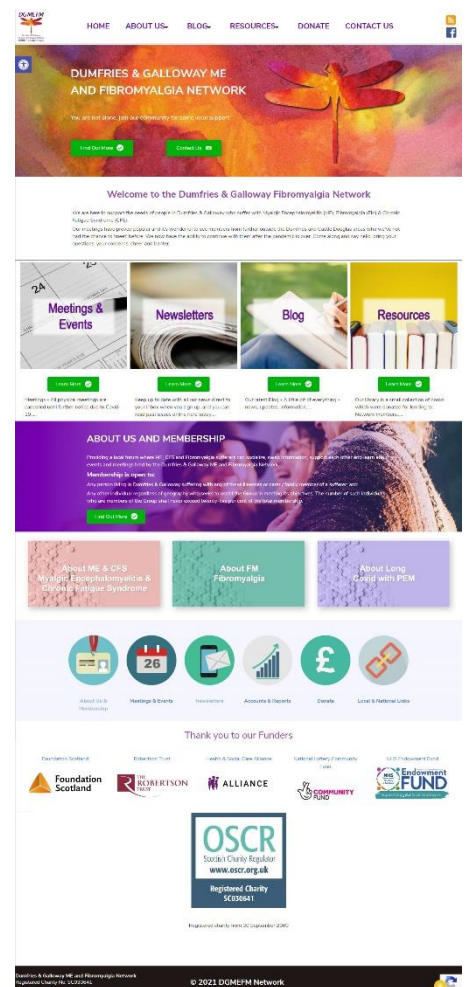
Amanda Stevenson, Team Manager for Single Access Point will join our Zoom meeting on Thursday, 23rd September at 2pm to talk about what they do and how and when to access the services.

New website

The Network was pleased to be able to work with Matt Kitson, of baggytmat Ltd, in order to redesign our website. The old one had grown organically and wasn't the easiest to navigate, with some of its content being difficult to find and follow. The new one should be better to look at and more functional too.

Over the coming weeks and months, we will be updating the information on the illnesses we support and a refreshed collection of links to find local and national support. Our meetings page will be kept up to date with what we have planned, there'll be an informative and fun blog posted regularly, and you'll also be able to read PDF versions of this newsletter.

This is some of the work that has been supported by Foundation Scotland funding.



Self-Advocacy Training by Action for ME

This workshop will focus on knowing your rights, getting your voice heard, and exploring the barriers people with M.E. and their carers face accessing services and support.

Led by Action for M.E.'s experienced team, this workshop will cover: what is advocacy, and how can I self-advocate?; tools, tips and suggestion to empower you to self-advocate; how self advocacy and advocacy services can support you to tell people, professionals and services what you want and need to self-manage effectively.

It will take place online on the 28th September 2-3pm. Register at <https://tinyurl.com/5frk9ejz>

Note that this is not being run by us, but is available to a Scotland-wide audience. AfME have run a class for us in the Network before and I think we all found it helpful.

'Gift Day' September 2021

It's that time of year again when we ask if you can make a donation towards our costs.

We don't have a subscription fee for membership of the Network but we appreciate any donation however small, as we need this support to carry on our main activities.

- You can donate by PayPal through our website - <http://dgmeffm.org.uk/donations>
For eligible donations there is a Gift Aid Declaration button on that page.
- You can post your donation with this form addressed to:
DGMEFM Network Treasurer, Thistledew, Albert St, Dalbeattie. DG5 4JP.
Please make cheques or postal orders payable to 'DGMEFM Network'.
- If you feel able to make a regular (e.g. monthly) donation please contact admin@dgmeffm.org.uk for our bank details.

With many thanks in anticipation.

✂-----

To DGMEFM Network:

I enclose my donation of £_____

Donor's details

Title ----- First name or initial(s) -----

Surname -----

Full home address -----

Postcode -----



If you are a taxpayer, please consider signing this declaration. *From your donation we can claim an additional 25% from the Inland Revenue e.g. for a donation of £10.00 we get an extra £2.50.*

I want to Gift Aid my donation to the charity DGMEFM Network.

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations, it is my responsibility to pay any difference.

Date -----

Signature -----



