

February 2021

DGMEFM Network

Support for ME, CFS, Fibromyalgia



Welcome all,

Well... where do I start...

Is it too late to wish you a happy, better new year? 2021 must be an improvement on 2020! I sincerely hope it is for all of us. With January gone, probably the darkest month of the pandemic, and vaccines rapidly rolling out, I hope the corner has been turned.

I need to apologise for the very belated Newsletter. You certainly haven't been forgotten about. The Network has been working hard and there's many exciting (well we are excited) developments to tell you about in the pages of this (no-longer home printed) newsletter. They include successful funding bids, helped in no small part by your wonderful generosity for our Gift Day, which shows the funders how much our work means to you. There is news of a part-time development worker who is going to take on several projects and will be getting ourselves more known to local Health and Social Care. We hope this will make the running of the Network more sustainable as we have all been struggling, with myself going through one of my worst and longest relapses in years. There are several new committee members and they are adding new ideas and drive to the Network. Welcome Eileen, Annie, Corrie and Diane. Thanks to Lesley who is stepping down as Secretary.

We also now have an innovative online craft project to add to our online weekly meetings. Corrie will be heading this up and it will be an excellent opportunity to learn a new skill, in a relaxed way, while enjoying the camaraderie of your fellow Network members. I hope this is something many of our members will enjoy and benefit from. Read about it and how to sign up on page 9.

Much of this has been prompted by the pandemic and the way it has re-shaped the world around it. There is much to be concerned about but there are also good things happening. Long-Covid research money may yet provide a treatment that will help us, but in the meantime, we need to prepare for the many new people who are developing very similar problems to our own. Our experiences, mixed though they may be, can be used to improve their chances and avoid the same mistakes we have suffered from.

Craig Woods

Online Get-Togethers Every Thursday 2pm – 3pm on Zoom.

February 11th Self Advocacy Training from Action for ME– see overleaf

February 18th An Anti-Poverty Advisor from DaGCAS will join us to tell us about this project and the help which may be available for those on low incomes, including anti-fuel poverty support, financial advice, etc.

February 25th A general chat and catch up.

March 4th We will take Dr Nina Muirhead's excellent ME/CFS Continuing Professional Development module together. See page 7 for more info.

To be announced We have yet to set topics for further meetings. We intend to have meetings on: Long Covid (with sufferers telling us about their experience); the new draft NICE Guidelines on ME (with Dr Purdie); there will also be social meetings and a get-to-know meeting with a Network member.

You can join us by downloading 'Zoom Cloud Meetings' on your smart phone or tablet, or go to www.zoom.us on your computer and 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.

Contact us:

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Self Advocacy Training

Action for ME have extended their self-advocacy training to Scotland and have offered us a session over Zoom on 11th February at 2pm.



AfME writes:- People with M.E. have told us they can struggle to communicate their concerns and needs effectively: *"It is difficult to get social services, the NHS and the care agency to listen to or understand my needs. It feels like a constant struggle and it affects my health adversely."* This training includes guidance to enable you to overcome such challenges and help yourself. To be a successful self-advocate you need to think about:

1. Your rights – including what support you might be eligible for
2. What is the issue – and what are your goals?
3. Effective communication – how to express yourself clearly.

The training will help you with these issues and point you towards further help if needed.

The training session will take up to 2 hours with a 'comfort' break in the middle. You can join using our usual Zoom link/meeting ID and passcode, but it will be led by AfME's trainers. I hope that it will help give us the confidence to make our voices heard and listened to.

Action for ME are also looking for volunteers to train to be advocates. Get in touch if you're interested and would like more information.

Meeting Report: Jill Hunter of Dumfries and Galloway Citizen's Advice Service

I asked Jill to join our 14th January Zoom Meeting to give us an update on the current benefit situation. We talked mainly about PIP (Personal Independence Payment) as it is most applicable to us. The Scottish Government is still planning to take control of this benefit and replace it with Adult Disability Payment. The rollout of this has been much delayed, and has been further delayed again, due to the pandemic. It's now expected to be piloted for new applications from Spring next year, with the rollout happening sometime in the Summer. The value of the payment will stay the same as the current PIP payment to begin with but Scotland may diverge from the UK rate over time.

The government has consulted on the design of the new benefit and, on paper at least, it seems to be a better system. The private companies who currently do the assessment will be replaced with assessors directly employed. Awards will be for a longer term than with PIP, especially for long-term conditions.

The other main points I took from the meeting with Jill were:

- She recommends that you always ask for help from DAGCAS (or the council's FIAT Team if you are over 65) to fill the form in or at least ask them to check it for you before you send it off.
- Ask for a medical summary from your GP instead of a supporting letter. This will show the conditions you suffer from and your treatment. It is also free rather than chargeable. Similarly send off your repeat prescription list.
- Ask for help with appeals. Mandatory Reconsideration rarely overturns the results but you need to go through this stage before you can appeal. Appeals are very often successful.
- Keep your award letter which shows where you were awarded points. This helps hugely when you have to reapply and renew your claim.
- Tribunals are recorded and you can request a copy of the recording. Assessments are not recorded and they are often inaccurate. You can request to record it yourself but this needs to be done on cassette, not digitally, and two recordings must be made, one for yourself and one for the assessors. Other recordings will not be considered.

- If your bad days outweigh your good you fill in the form as if it is a bad day. If you can't sustain the activity or you are in pain when doing it, or it causes your condition to worsen you must say in every answer on the form or when speaking to the assessors.
- If your health-related benefits are stopped until an appeal takes place DAGCAS will help get you income-based benefits in the interim if you qualify.
- Don't be put off applying. If you get nothing now you have nothing to lose and a lot to gain by making an application. You will be helped and supported by DAGCAS. Renewals are more stressful, but you can get help with those too.

DAGCAS Anti-Poverty Scheme

Emma Munro will join us on our 18th February Zoom meeting to talk about DAGCAS's Anti-poverty scheme. You can refer yourself and they will look into the benefits you should be claiming, they can offer fuel-poverty advice and help with grants, energy efficiencies and making savings on your power bills and they can also look at your finances. It should be an informative meeting.

Long-Covid

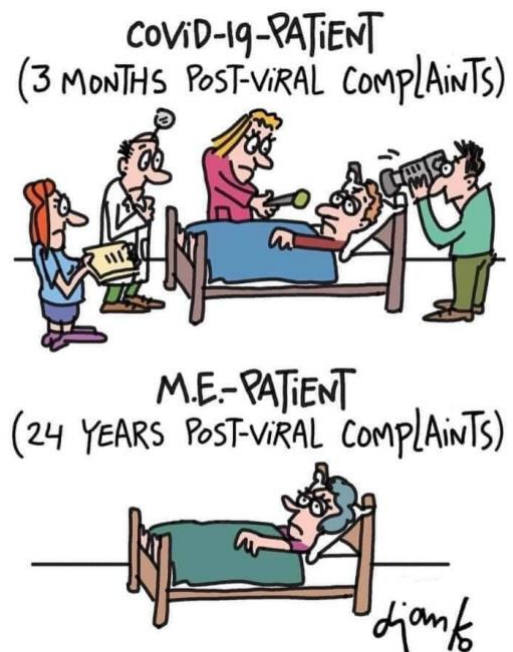
You can't have failed to hear about Long-Covid in the press. It is becoming an ever-growing problem leaving a large minority of those who fall ill with Covid with an ME-like illness. Along with the natural supportive feelings we have towards those unfortunate enough to develop Long-Covid there has been some upset and resentment of the amount of scientific and press interest these patients are getting. This is only natural given how little attention and support has been directed towards us over the years. If ME/CFS had had adequate levels of research there may have been a drug or treatment or prevention advice ready for the large number of people who now also face minimal and confused support.

Long-Covid is however bringing large amounts of funding, with the US Government pledging \$1.15 billion towards Long-Covid research. Much of this money could be directed towards ME researchers – and it is very likely to bring developments which will benefit many of us, with treatment or even a cure a possibility. Indeed some ME research projects are already benefiting. At the same time, in the UK, many of the usual suspects, the Graded Exercise Therapy and psychological proponents are moving their attention and treatment plans – with no evidence - from ME on to Long-Covid. They are potentially soon to be out of ME work (see the NICE Guidelines story) so this could be very convenient timing for them.

Our Long-Covid Policy

With the large increase in Post-Viral Fatigue Syndrome and ME-like patients we needed to develop a policy for Long-Covid sufferers.

We feel that mutual support from people in a similar situation, who can offer the vital advice to rest and pace in the early days of the illness means that our Network is best placed to offer this support locally. With 3,369 people tested positive for Covid-19 in D&G we'd expect over 400 people to suffer long term chronic illness based on a conservative percentage estimate based on those remaining chronically ill after SARS Covid-1. These are only numbers from the confirmed cases - the numbers who've had Covid-19 without a positive test will be much higher. Long-covid is affecting people who were mildly impacted by Covid-19 too.



The cardinal symptom that means our Network is best placed locally to support at least a large subset of sufferers is Post Exertional Malaise/Post Exertion Symptom Exacerbation. This is what makes it most similar to ME and which may mean that these people are at some point diagnosed with ME/CFS in the future. Those with Long-Covid are also suffering brain fog and memory issues and unrefreshing sleep too. We would hope that by hearing the experience (good and bad) we have to share and with our encouragement to rest and pace, especially in the early days, that it will offer these people the best chance of recovery from post-viral fatigue but if it were to develop into long-term Long-Covid or ME that the illness effects will be milder and more manageable.

The Network hopes to be jointly producing the ME Association's excellent information leaflet on Long-Covid and distributing it within D&G.

Craig Woods

Covid-19 Vaccination

It is likely that you have concerns about how the vaccination might affect your ME or Fibromyalgia and many of us will be considering whether to take it when it is offered.

Cort Johnson of the excellent Health Rising website, which we often feature excerpts from, asked top ME/CFS doctors in the USA for their opinions on this question....



This from Dr Nancy Klimas, who I respect greatly, is concerning: -

“COVID kills people. It kills people with over activated and damaged immune systems preferentially – and that is what ME/CFS is all about. So while there certainly is a risk of an ME relapse with these hyper reactive vaccines (the first wave to be released), you have to weigh the possibility of an ME relapse against the risk of death from COVID.”

Dr Charles Lapp:- “Since people with ME/CFS frequently suffer immune dysregulation, many wonder if they should be considered “immune deficient.” Our opinion is that many patients have an UP-regulated immune system and fend off viruses readily, so they rarely fall ill. If you are the type of individual who “catches every virus that comes along,” then you are probably in the minority of DOWN-regulated patients and should highly consider the vaccination when it is available.” He also thinks the vaccine unlikely to cause a flare up.

Of the 7 doctors Cort polled 2 said that they were taking a wait-and-see approach for their ME patients, and they'd know by the time the vaccine was readily available. Five of the doctors either recommended or very strongly recommended their patients take the vaccine with no one advising against (the usual provisos against previous allergic reactions standing, of course).

Dr Shepherd of the ME Association has continually updated advice about the vaccine in people with ME. This an extract from their latest leaflet regarding whether vaccination is right for you:-

MAKING A DECISION

When it comes to deciding if you are going to have a COVID-19 vaccine people with ME/CFS are going to have to make an individual decision that is based on the information that we have so far:

1. A risk that some or all of your existing ME/CFS symptoms may be exacerbated for a short period of time.
2. A lower risk of a more significant or prolonged exacerbation of ME/CFS symptoms.

3. The possibility that once very large numbers of people have been vaccinated we will learn about some rare or more serious side effects that could be relevant to people with ME/CFS.
4. Obtaining a high degree of protection from Covid-19 in return for a risk of exacerbating ME/CFS symptoms.

Dr Shepherd writes “Life is full of risks and based on what we know so far on safety and efficacy of these vaccines my personal view is that taking a risk of having an exacerbation of existing ME/CFS symptoms is a small price to pay for having a high degree of protection against a life threatening infection that we are all going to have to live with, just like flu, for the foreseeable future.”

Unfortunately I haven't seen advice for people with Fibromyalgia. Much of the same considerations will be in play however.

The ME charities, including the ME Association are campaigning for people with ME to be included in group 6 of the vaccination rollout, which will happen after the over 65s group. This phase is for people with a chronic neurological condition and mentions examples such as MS. ME is not mentioned as one of the illnesses but is classified in the UK and by the WHO as a neurological condition and there's a very high probability of a prolonged relapse were someone to catch Covid-19. It seems that this could be an argument we may have to have with our own GPs.

Fibromyalgia, classed as a disease of connective tissues, and not neurological, doesn't have the chance of being included in this group.

Craig Woods

ME/CFS NICE Guidelines

In November 2020 the National Institute for Health and Care Excellence (NICE) issued their draft revised guideline for ME/CFS diagnosis and management. National groups such as ME Association, Action for ME, and #ME Action UK, have each broadly welcomed the revision and responded to the consultation with due praise, remaining areas of concern and their recommendations for improvements. The finalised guideline is expected Wednesday 21 April 2021. Whilst we have our own Scottish Good Practice Statement on ME-CFS, the English NICE guidelines have been very influential over our standard of care and often deferred to by our GPs and health care practitioners. We understand that the Scottish guidance will be reviewed in due course in the wake of the NICE guideline revision. Of particular note, the revised guideline actively discourages Graded Exercise Therapy (GET), and while Cognitive Behavioural Therapy (CBT) is still prominent it is put in proper context. The following is a brief summary of some of the recognition, changes and recommendations that have been made by the NICE guideline committee in the draft document.

The recommendations in the Guideline strengthen our case for the kinds of changes in local health and social care provision that we have been asking for.

Principles of Care

- recognition of the lack of belief by health and social care professionals about ME/CFS as a real condition, and lack of understanding about what it is and the impact it has, and what this means when providing care.

Suspecting ME/CFS; Diagnosis

- a provisional diagnosis of ME/CFS where all the 4 key symptoms (debilitating fatigability, post-exertional symptom exacerbation, unrefreshing sleep and cognitive difficulties) last for a minimum of 6 weeks in adults and 4 weeks in children and young people. Advice to be given on symptom management for people as soon as ME/CFS is suspected.
- Reduction from 6-month delay before diagnosis to 3 months with referral to a ME/CFS specialist team at 3 months to confirm diagnosis and develop a management plan.

Assessment and care planning by a specialist ME/CFS team

- a personalised management plan should be developed as soon as the person's diagnosis is confirmed, and recommendation for home visits to people with severe and very severe ME/CFS to carry out the assessment.

Access to care

- improve access to care based on potential barriers of physical accessibility, time constraints of appointments, and common sensitivities such as to light and noise.
- flexibility and specific support needed by those with severe or very severe ME/CFS who have little contact with and support from health and social care services.

Supporting people with ME/CFS in work, education and training

- better communication between health and social care professionals and training and education services to develop a shared understanding of the needs and impairments of people with ME/CFS and how to provide them with appropriate educational support

Multidisciplinary care

- most people with ME/CFS can be managed in primary care after their diagnosis is confirmed and they have a management plan agreed. However, the committee acknowledged the lack of confidence that non-specialists can have in managing ME/CFS and they recommended support from a ME/CFS specialist team

Managing ME/CFS

- a detailed assessment in areas of current activity and evaluation of rest and sleep, to establish an individual activity pattern within the person's current energy envelope.
- support people to stay within their energy envelope and aim to prevent their symptoms from worsening, and support them to increase their activity if possible.
- specialist advice and additional care for people with severe or very severe ME/CFS
- people with ME/CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in ME/CFS.
- there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS and not to offer any programme based on fixed incremental physical activity or exercise, for example graded exercise therapy or structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS

Medicines, including medicines for symptom management

- medicines or supplements should not be offered as a cure for ME/CFS.
- a cautious approach to medicines prescribing, which includes starting the medicine at a lower dose than in usual clinical practice and monitoring how the person responds before adjusting the dose
- for children and young people prescribing should be initiated under the supervision of a paediatrician with expertise in ME/CFS

Dietary management and strategies

- people with severe or very severe ME/CFS are particularly at risk of problems associated with eating and are likely to need additional support and referral to a dietitian who specialises in ME/CFS

Psychological support: cognitive behavioural therapy

- CBT is not a cure for ME/CFS and should not be offered as such, but may be useful in supporting people who live with ME/CFS to manage their symptoms and should only be offered in this context

- CBT is only considered for children and young people with ME/CFS who have been fully informed (along with their parents and carers) about the principles and aims of CBT and that their cognitive and emotional maturity is taken into account.
- CBT could be supportive for people with severe ME/CFS but because of the severity of their symptoms it is important to be more flexible and adapt the delivery of CBT to accommodate people's limitations

Review

- at least annual reviews for adults, and more frequent review for children and young people to take into account changes in their ME/CFS as they develop, involving a paediatrician.

Training for health and social care professionals

- all health and social staff who deliver care to people with ME/CFS should be trained so they are able to provide the care in this guideline.

New Online CPD Training Course for Health Professionals about ME/CFS

An initial step in health and social care staff training to be promoted locally between Action for ME and ourselves is a recently developed online module for health professionals about ME/CFS.

The CFS/ME Research Collaborative's Medical Education Group which is led by Dr Nina Muirhead (an NHS consultant with M.E.) has launched in partnership with StudyPRN an online course for medical professionals about ME/CFS.

This has been a team effort with members of the group comprising medical professionals with an interest in the condition, charity representatives including the ME Association, Physios 4 ME, and the CMRC Patient Advisory Group.

The online course is in the form of a number of case studies. It can be taken by anyone with an interest in ME/CFS, will count towards continuing professional development (CPD) and result in a certificate.

GPs and other healthcare professionals will

read case studies that aim to typify the kind of patients who may or may not display symptoms of ME/CFS, and will then be asked to decide what those symptoms might be indicating, what diagnosis is appropriate and what management advice and/or medications to consider.

If they select wrong answers, then the module will explain why those answers are wrong and suggest what things they might have missed as well as indicating the correct answer. It also touches on Fibromyalgia and the overlap, as well as giving an example of Long-covid.

The hope is that participants come away from the course with more knowledge about ME/CFS than they had before, and that we can help increase medical education and awareness.

For our **March 4th Meeting** you too will have the option of taking the course using Zoom's screensharing feature. You then will be able to tell your health professionals about it.



Funding and Development work

Following a successful application, we are pleased to have received a grant of £4620 from Foundation Scotland's Community Response, Recovery and Resilience Fund, to be used by 31st May this year.

The grant allowed us to appoint a part-time Development Officer to 'raise awareness of the network and provide increased support to people living with ME and Fibromyalgia, particularly those impacted by COVID-19.'

It will also cover the cost of materials for a new Craft project which we'll be running over the next few months – see following pages.



We were also successful again with our second application to the Robertson Trust and are grateful to have received another year's funding from them of £1000 towards our running costs.



Gift Day thanks

Many thanks to all of you who were able to contribute to our Gift Day last Autumn, and for other donations over the year. This helps greatly towards the cost of main activities including the newsletter and website.

A big thank you as well to Bryan Woods who paid for the cost of our Foundation Scotland application, and has contributed a large number of stamps towards our newsletter distribution.

Grace Cardozo, Managing Director of Sleeping Giants helped us secure the grant from Foundation Scotland and she has recently submitted an application on our behalf to the Health and Social Care Alliance Scotland (the Alliance) for a grant from the Self Management Fund which they administer on behalf of the Scottish Government. This would allow us to commission further development work in the summer – more on that in the next Newsletter if we have a successful outcome.

In the meantime, we are pleased to welcome Senga Armstrong to the role of part-time Development Officer, funded by Foundation Scotland until the end of May:



'I am very much looking forward to working with the DGMEFM Network and meeting members soon. This is an exciting time for the group with several developments to be taken forward and you will be able to find out about these through the newsletter.

The main priorities are: undertaking a targeted promotional outreach campaign, develop robust partnerships with local agencies and look for opportunities for joint work e.g. working in partnership with Action for M.E. promoting the CPD module to health professionals.

I have supported a number of groups across various geographical locations of Scotland and Dumfries and Galloway is a familiar region of the country to me. My background is varied having been self-employed; conducting research, a lecturer in F.E. colleges and delivering training for a national charity based in London.

If there is anything you would like to know more about please contact me on senga@dgmefm.org.uk My usual work pattern is every Thursday and Friday afternoon of each week.

Committee news

As with all our meetings since last March, our AGM in October was held online by Zoom. The advantage to Zoom is that members can get together regardless of geographic distance. As a result, we are grateful to have four new members of Committee: Annie Shreenan, Corrie Schrijver, Diane Bond and Eileen Longworth; joining Craig, John, Lesley, Nancy and Paul who each continued with their previous roles. However, Lesley asked to step down in January. We owe her many thanks for all her work and support over the past few years.



A screenshot from our 21st Jan get-to-know meeting with our Development Officer, Senga and Doctor Purdie.

Craft project

Behind the scenes, we have worked hard to get the craft project started.

The first three workshops can now be booked. All workshops will be on Zoom.

Places for the workshops are limited and open to DGMEFM Network members only.

Please book your places as early as possible.

Corrie will kick off the Craft project on the 16th of February with a workshop on wet flat felting.

When you are successfully booked into two workshops, you will initially go on the reserve list for any more you book, to give others a chance. Please number according to your 1st 2nd, 3rd etc. choice.

Please check the DGMEFM Network website blog, Get Crafty Facebook page, and main Network Facebook page for more details and updates.

Once your place on the workshop has been confirmed, you will be asked to provide your full address.

A kit, including materials and tools will be posted to you the week before the workshop. If you are unable to attend the workshop, please let Corrie Schrijver know two weeks before the workshop so your place can be offered to someone on the reserve list before your kit is posted. If you do not provide your address two weeks before the workshop your place will be allocated to the first person on the reserve list.

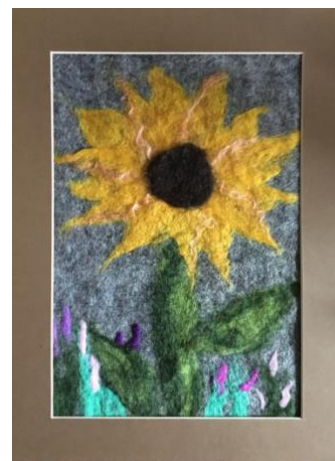
These workshops are free of any charges. All materials for the workshops are funded by the grant from Foundation Scotland.

Beginners Wet Flat Felting workshop

With DGMEFM Network Committee member Corrie Schrijver.

Tuesday February 16th, starting at 11.00am, to 13.00 hrs with a short break.

In this workshop we shall be creating a simple picture by felting wool. You will learn how to overlay different colours of wool, to create the patterns you want. Then you will learn how to bind the layers of wool together by agitating it with warm soapy water, which will lock the fibres together. It is possible to make lovely felt pictures to be framed, or you can make soft or dense pieces of felted fabric to your own design, which you can then use for a sewing or other project.



Beginners Silk Painting Card workshop

With DGMEFM Network Committee member Paul Thompson.

Wednesday March 3rd, starting at 2pm.

This workshop is an introduction to painting on silk, to make greeting cards using designs which have been prepared with a gutta outline. The gutta lines resist the paint spreading beyond their border. It's an easy introduction to painting on silk as the silk is attached to a backing paper, and therefore more biddable to paint.

The workshop will begin with a brief instructional video.

Then we'll work together on one of the 5 designs.

Beginners Jewellery Making workshop

With DGMEFM Network member Kim Jakobsen.

Tuesday 16th March, 1.30pm to 3.30pm with a short break.

Imagine thinking, "I'd love a new necklace to spice up my favourite dress," or "I wish I had some fancy new sparkling earrings!" Or perhaps you long to give truly unique handmade gifts that will be treasured and cherished by your family and friends. Well, after you've attended this zoom workshop, you can put those thoughts into action. The kit you will be sent is full of sparkling treasures for many projects.



Other confirmed Zoom craft workshops are;

March 29th Rag Rugging with Penny Lilley, 11.00am start
April 12th Learning Cross Stitch Embroidery with Eileen Longworth, 11.30am start
April 26th Fold-out Greeting Cards with John Bell, 1pm start
May 21st Crochet Granny Squares with Corrie Schrijver, 11.00am to 1pm
Early May workshop TBA

More details to follow on our Facebook groups and by email.

Corrie Schrijver

All workshops to be booked by emailing to; corrie@dgmefm.org.uk

My Experience of Catching Covid-19

I have had ME for a very, very long time (20 years) and have had years where I have had an almost 'normal' life and I have a difficult relationship with acknowledging my condition.

I was working part time at the start of march at Gretna Green in the tiny museum where the weddings take place. I had just begun my employment on 17th February and we had people coming from all over the world: Canada, Israel, France, Belgium, USA, Japan, Malaysia right up until the 15th of March and we also had visitors from China until the end of February. There were many occasions on which we were concerned about people coughing as it was such a confined space we were working in.

I became unwell on the 12th march. It started with a slight cough that evening and then overnight I had a very high fever. In the morning I had no fever but that day I felt lightheaded; I did not think I had Covid. Two people that I work closely with had been unwell, with colds. At no point was Covid suggested. On the Saturday I drove to work, but I had the most terrible stomach pains and had to rush to the toilet several times while at work. They did not send me home. That same day I developed a blinding headache which I initially put down to dehydration. On the Sunday I could not move. I had woken up and got dressed; my stomach issue had lasted only around 12 hours, but I had only been up for around two hours when I felt a profound and debilitating fatigue sweep over me. I could not even sit up; a feeling familiar to me from my CF. I lay down and immediately feel asleep. This pattern would continue for the next couple of weeks. Rising, fatigue, falling asleep, accompanied by the most awful muscular pains, mainly in my legs. The headache persisted too. I did have a cough but it never concerned me as it was the strangest cough; it felt as though I had something in my throat, an irritation. I had only had it on the first night and then hadn't had any cough at all for a few days. The cough came mainly in the evening although sometimes I would have a short bout of coughing through the day. I still did not think I had Covid. What I had did not relate to what I was seeing and hearing about on the television. However, around 5 days in, I had to call my doctor for an inhaler. I have an allergy to cats and dogs and sensitivity to certain dusts, such as when we have had building work done. I don't have Asthma as such. I was struggling to get a deep breath; I felt as though my breathing was shallow at times and climbing stairs was such a tremendous effort. I was prescribed the inhaler but not asked about my other symptoms nor did I offer any further information as I did not think I had Covid and my GP said it was probably an ME relapse I was having.



So the weeks progressed, but my recovery did not. The cough went after about 3 weeks. I remained permanently exhausted, with regular persistent headaches and muscular pains. It took a tremendous amount of effort to even move to another room. In June, I eventually phoned my GP as I was concerned that I was not recovering. This was a different GP that I had not spoken with before. He seemed very interested and wanted me to recall in detail exactly how I had been in March. Twice he asked, almost in disbelief, if I was sure I hadn't been asked about the possibility of Covid at that time. I confirmed I had not. After a very lengthy discussion he

advised me that he considered that I had had Covid and that I was now suffering from what they were referring to as 'long covid'. He went on to say that the antibody test was not available on the NHS and nor was it reliable. He said that all he could do currently for long covid patients, he said he had around 5 already, was to refer to the respiratory clinic for x rays and lung function tests. He said that this would get the ball rolling so to speak and get me in the system meaning that I would have access to treatment when it became available, which he seemed to know something about, saying that they were beginning to work on treatments and care. It might be worth noting that my GP is in Glasgow. I had my xray done in August but did not get the result until the end of November. Thankfully it was clear. I am now due to attend for a lung function test in Glasgow.

I would say that I began to feel a little better around September. That is when I stopped having the headaches so regularly although I do still get cluster headaches. I would say that I am now around 60% better. I still occasionally fall asleep during the day, perhaps once or twice a week. My brain fog is so much worse than before though. I think that is the one main regression that I have had in terms of my ME/CF. Although I did also have a head injury due to an accident at the end of September so it is difficult to tell if my memory loss and brain fog are due also to this. I think perhaps when I had Covid, although it cannot be confirmed, it was not so bad due to the fact that I take a huge amount of supplements to enhance my immune system. I can never be sure of course, nor to an extent can I be sure that what I have is not a relapse of my ME, caused by Covid. It feels very confusing.

As I had mentioned, I had got to a place where I had an almost normal life. Of course, I was not able to do all the things that other people can do. My body is constantly in varying degrees of pain and I can only ever do slow short walks and activities, but it had become a normal that felt ok, acceptable. I could pretend I wasn't unwell. I could go to work, albeit very part time and just for a few hours at a time. I have always pushed myself to my boundaries but I have always known where my boundaries are. I now feel as though I am living with a new poison in my system. I am taking the supplements, eating well, and in fact lost two stone from September to December. But I am now so limited in what I can do. I will get moments when I suddenly have to use my inhaler because I feel as though I can't get a breath, I also am in constant pain, greater than that which I had before March and I am currently in the midst of cluster headaches which I find quite debilitating. Where I previously would have days where I felt I had some 'mild' energy, I am now constantly tired and no amount of sleep improves it. In fact, I am back to where I was at the beginning of my ME journey, on wakening, feeling as though I have not slept and need another 10 hours!

Helen King

New research suggests cause for irritable bowel syndrome

A team of researchers from the University of Leuven has published a study offering more information on the mechanism causing some people to react violently after eating certain foodstuffs.

Irritable Bowel Syndrome (IBS) is a condition that leads some people – about 11% of the global population, more often women than men – to have a violent reaction to certain foodstuffs, with stomach pain, bloating, constipation or diarrhoea and other symptoms.

The condition has also been associated with chronic fatigue syndrome, depression and anxiety. The gravity of symptoms ranges from mildly inconvenient to debilitating.

Despite the presence of the condition being well-known, the exact causes were not. Now, however, a study using mice and some humans has opened the door to a new explanation of how IBS comes about.

Put in the simplest terms, the study suggests that an infection in the gut can lead to a change in the immune system in the intestines, so that some types of food are then regarded by the body as harmful. Even after the initial infection has passed, the gut continues to react to some foods as if they were pathogens, leading to the symptoms common in IBS cases.

The study into mice found that immune cells in the gut known as mast cells responded to an infection induced in the mice caused by the bacterium *Citrobacter rodentium*. However, the mast cells also saved an image of



harmless food cells that happened to be present at the same time. Later, when the infection had passed, the mast cells retained the image of the food cells, which were now considered pathogenic, and the body reacted accordingly.

The study does not go so far as to suggest a method of preventing or even treating IBS, but it does open up a new avenue for research. "These patients are often not taken seriously by doctors. The lack of an allergic reaction is used as an argument that it is all in their heads and there is no problem with their gut physiology," Professor Guy Boeckxstaens, gastroenterologist at KU Leuven and lead author of the study, told the VRT. "With these new insights, we are providing further evidence that we are dealing with a real disease." The study is published in the latest edition of the journal Nature.

Alan Hope, The Brussels Times, 14 January 2021



Odd One Out

From our end of the year quiz: For each collage which person is the odd one out, and why? The answer is on our Facebook page, or get in touch for it.

Member contributions are very valued.
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:
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