

Richmond & Kingston

ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

NEWSLETTER

No 1, 2022

Inside — Crafting Fun — Free Audio Books — Annual General Meeting Report — **██████████**'s Ten Questions — And More...

Implementing the New NICE Guidelines

The issuing of the National Institute for Health and Care Excellence's revised clinical guidelines for the treatment of ME on 29 October 2021 constitutes a major step forward in respect of the treatment of our illness. At last, ME is described in an official document, one that is aimed primarily at health and social care professionals, as a physiological condition. As for the previously recommended treatments for ME, cognitive behaviour therapy is now presented as being of limited usefulness, and the downright dangerous practice of graded exercise therapy is no longer to be prescribed

The main question facing us now is the degree to which the health professionals will change their approach to ME to ensure that it is in line with the new guidelines. As I observed in the last newsletter, the medical world can be strangely slow to adopt practices that subsequently come to be recognised as

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beneficial, and, no doubt with this in view, various ME campaigning groups have produced material which is aimed at enlightening health professionals and especially our usual first contact with them — our GPs.

The ME Association has published a pamphlet that presents in a clear manner the key features of the new guidelines, and this will be useful for people with ME and their carers when they are discussing the illness with GPs and other health professionals. It can be downloaded, free of charge, from <https://meassociation.org.uk/wp-content/uploads/An-ME-Association-Summary-of-the-2021-NICE-Clinical-Guideline-for-MECFS-December-2021.pdf>.

ME Action's 'Dear Doctor' campaign is aimed at encouraging GPs and other health professionals to read the new guidelines and to recognise the fundamental changes that they present. A template of a letter to GPs can be downloaded from <https://www.actionforme.org.uk/get-support-now/info-and-support-resources/living-with-me/me-training-for-gps-template-letter/>.

ME Action has produced a template of an e-mail which people with ME can send to their GPs, outlining the key changes to the treatment of ME that are presented in the guidelines. It can be obtained at <https://www.meaction.net/2021/11/09/tell-your-doctor-that-get-is-gone/>.

Book Review

██████████ reviews Dr Deepak Ravindram's *The Pain-Free Mindset: 7 Steps To Taking Control and Overcoming Chronic Pain* (Vermillion, 2021).

* * *

The Pain-Free Mindset is a fascinating book which could transform the way you think about pain and potentially significantly reduce your suffering from pain. But it has a dreadful title — he is neither promising all chronic pain will disappear, nor is he suggesting that it is 'all in the mind'. Let me explain.

The Man and the Idea: Dr Ravindram is an NHS pain consultant who writes sympathetically and with informed insight about chronic pain management. He starts by explaining how our understanding of pain has shifted dramatically in recent times, and goes on to lay out an holistic programme of steps to manage chronic pain. The word 'Mindset' is an acronym of the various tools we have for managing pain: Medication — Intervention — Neuroscience and Stress Management — Diet and Nutrition — Sleep — Exercise and Movement — Therapies (of the mind and body).

The start point is to understand where you are in your pain journey; he provides two questionnaires for a self-assessment. Then he explores the seven steps that can help relieve suffering, and finally offers a blueprint for integrating them to create a personal programme to take control of your pain.

Nociception and Pain: Pain is a danger signal and an alarm system for the body. We learn through pain to avoid things that can harm us (not to touch fire, not to walk on a broken leg). Our very clever nervous system learns about danger and tries to help us avoid it. Which is usually good, but not always.

And to understand why these steps might help, he first explains how our understanding of pain has developed recently; we now understand there to be two distinct issues: nociception and pain.

Nociception is the harm signal from an insult to the body (such as a cut or a fracture) that activates chemicals and channels in the skin leading to a perception of hurt. A signal is then sent via the spinal cord to many parts of the brain dealing with memory, emotion, logic, fear and worry, leading to a final output message. If that message is that there is danger, we feel pain. If not, we don't.

Pain is the subjective experience of actual or impending harm; it is there to protect us from harm. This perception of danger can come from sensations within the body or from the external environment.

But it is possible to have insult without pain (my friend ran 16 miles of a marathon with a fractured wrist without pain yet had 18 months of painful problems after).

And it is also possible that we can experience pain when the original insult is healed (pain without nociception) because our brain is interpreting that there is danger of harm. Pain is always real, but, for example, it may come from memory rather than current physical experience.

So while pain is there to protect, it can also negatively affect our quality of life and wellbeing. In chronic pain, we frequently become increasingly sensitised to the signals as the body desperately tries to avoid the danger in a vicious circle.

People are mostly only offered medication and/or intervention, and nociception responds well to this. The problem is that pain not associated with nociception does not. When pain has been present for at least three months, it is likely that nociception is not the main issue.

What Can Be Done? His first point is to suggest a holistic multi-faceted approach, rather than a complete reliance on one option.

i) Medication: He categorises and explores different types of pain; chronic fatigue, fibromyalgia and irritable bowel syndrome are all included in nociplastic pain (where drugs and interventions are not usually helpful). Neuropathic pain can be helped by drugs/intervention, but are not usually fully effective on their own. He then reviews the pros and cons of different medication according to the type of pain and the person you are, including a brief questionnaire for you to assess your current medication. Finally, he makes some suggestions for an approach towards reducing or removing medications (and hence reducing side-effects without reducing efficacy). His explanation of the placebo effect is also helpful in preparing the way for some of the other suggestions.

ii) Intervention: This can be very effective for nociception. But more careful evaluation is needed before surgery or injections as chronic pain may not

respond to this approach. There is a significant risk of misdiagnosis; many people have changes in their body that, if they are identified in conjunction with pain, can be assumed to be the cause. But many people with the same issues live happily unaware and pain-free. Our expectations of surgery and injections are that they will provide the solution. Some recent research on actual surgery versus pretend surgery for back pain showed no difference between the groups' reduction in pain (a placebo effect). And surgeries themselves may result in post-operative pain. Before opting for intervention, consider the benefits, risks and alternatives, including doing nothing.

iii) Neuroscience and Stress Management: In this part, he delves more deeply into how pain works. The mind has been described as having three parts: a logical rational human; a computer with memories (which you may not be able consciously to access but that affect you, like trauma); and a reptile, hard-wired for danger that reacts emotionally, instinctively and faster than the other parts in response to anything it considers harmful. This one does a lot of the damage! Stress reduction is very helpful in reducing chronic pain, and he describes some techniques that have been shown to help (for example, mindfulness/breathwork, taking a positive approach to life, pacing, developing an emotional support network).

iv) Diet / Nutrition: There is a growing belief that increasing levels of poor nutrition (from processed foods and fresh food with low nutritional levels) plus use of antibiotics have led to changes in the gut and brain, resulting in immune dysregulation (among other things), and that these changes can contribute to fatigue and central sensitisation. He explores the anti-inflammatory diet and its role in reducing pain.

v) Sleep: Poor sleep and pain tend to go together. If sleep can be improved, then typically pain is helped. He describes some (possibly familiar) techniques for helping with sleep.

vi) Exercise and Movement: Some of this chapter seems helpful: exercise can help pain by improving sleep, reducing inflammation, influencing mood and improving energy, but 'start low and go slow'. Exercise reduces some tension which exacerbates chronic pain. But this was not written for people with ME (although he maybe thinks it applies there too), and some aspects of the approach in this chapter seem the most controversial to me.

vii) Therapies (of the Mind and Body): Here he gives a brief introduction to many therapies that might help, accepting that this will be an individual choice (and one for which we will almost certainly have to pay!). He says the key is relaxation. He also says that the results are as good as medication or intervention for many pain conditions (and I know, for example, that mindfulness has been shown to impact significantly upon chronic pain).

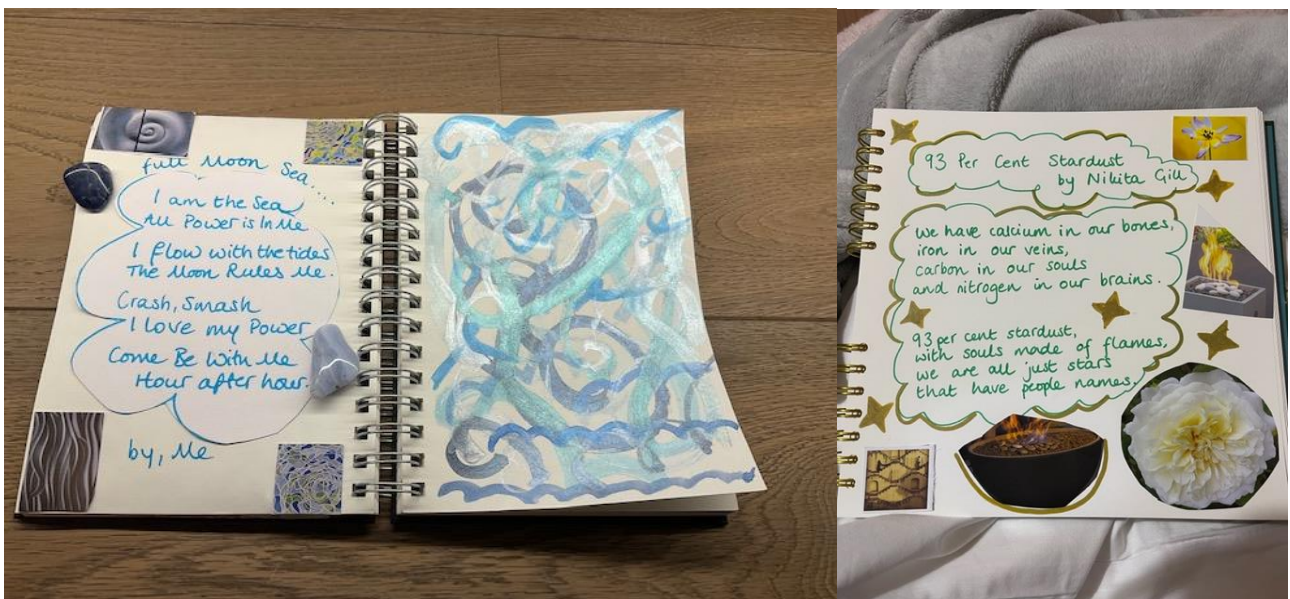
Finally, he discusses how to put it all together — putting options into different groups, from 'done for you', through 'done with you', to 'done by yourself' — and talks about how to build new habits, and making a plan for a flare-up.

Conclusion: It's not a simple message, but the book is well written with plenty of real-life examples and practical suggestions. If you have chronic pain, I'd recommend this book as a way of guiding you to more successful strategies for pain management, by adopting a more holistic (and gentle) approach.

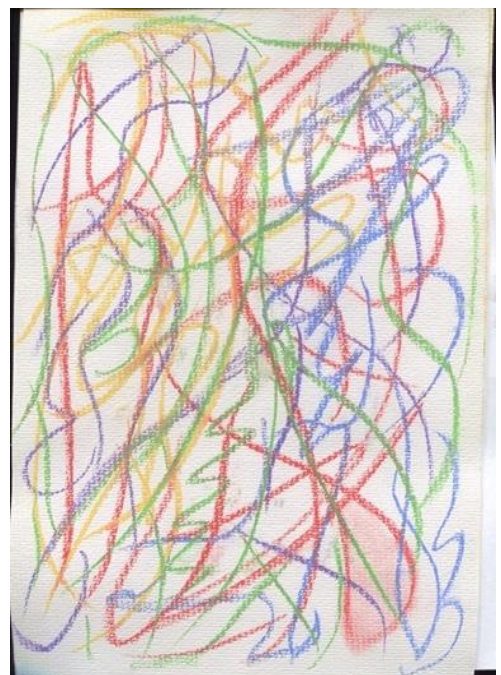
Hidden Talents – Crafting

The Richmond and Kingston ME Group's monthly crafting meetings on Zoom are uncovering hidden talents among group members.

█ writes and illustrates poetry, and creates collages.



█ 'doodles' (some of us wish we could doodle like that).



Both [redacted] and [redacted] recently experimented with ‘mindfulness breathing and directed drawing’, linking the drawing of spirals and breathing, and found this very relaxing.

More recently we have been joined by two embroiderers. [redacted] is using the group to work on a really complex and lovely shop scene.



[redacted] has traced the Picasso picture *Guernica* onto a canvas and is embroidering this!





On a more modest level, [REDACTED] has tried origami.

Her major achievement is a jumping frog, although this is more impressive when you can see it in action!

The crafting sessions on Zoom (monthly for 40 minutes) produce a companionable but quiet shared environment for individual activity. The range of activities is immense, with illustration, drawing, doodling, collage,

embroidery, calligraphy and origami, but also reading, planting plans, editing, proofreading, jigsaws and undoubtedly many more.

There are no rules; bring any activity you want to do for half an hour or so, and join us on Zoom. If you want to, show us what you're done; but if you prefer, attend in silence or with your video off or both. Come for the 40 minutes, or part of it — it will be lovely to have you with us.

Audiobooks and On-Line Books

Did you know that you can borrow audiobooks and on-line books free of charge with Libby? If you belong to your local library, there is an app called Libby that you can use to download audiobooks and books and to access newspapers to read, all free of any charge.

First, you need to *download the Libby app* on to a phone or tablet.

Then *you need an account*. You get this by using your library card number and PIN. My card was out of date and I went to the library to sort it out; they gave me a new card and PIN in under five minutes.

But there is no reason why this couldn't be done by phone — it just might depend on how helpful your library is — my experience is that librarians are pretty keen to help you access resources. (If you try this, please do let me know how it works.)

The joy is that you then have access to the most amazing set of resources.

- ★ Audiobooks: I have access to over 13,000 audiobooks, of which 10,000 are currently available, and you can reserve any resources you want that are currently out on loan.
- ★ Books to read: I can access 45,000 titles, and over 35,000 are currently available to borrow.
- ★ Magazines: 4000 titles are available.
- ★ Newspapers: not *The Times*, but many others, including the *Daily*

Telegraph, and the *Independent's* comment section, that are usually behind a paywall.

I am still learning how to navigate the site to find the books that I want. If you know the author or title, this is easy. I have just tried browsing, which enabled me to find a new author for a low-risk trial.

If you like to read and want to listen or read on a device, I really recommend this app.

██████████ (with thanks to ██████████)

Ten Questions

This time answered by ██████████.

- 1) **How long have you had ME?** I was diagnosed in 2015, though I had symptoms many years before this.
- 2) **What was the trigger that started it off?** I really can't remember a specific trigger.
- 3) **What is the worst thing about having ME?** A feeling of helplessness.
- 4) **Has anything good come of it?** Nothing.
- 5) **What treatment (prescribed or alternative) has helped the most?** Mind fullness and Gabapentin for brain fog and pain.
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Homeopathy.
- 7) **What do you like doing on a good day?** Everything just to feel normal for a day.
- 8) **Do you have any tips for getting through a bad day?** Meditate and sleep, sleep and sleep.
- 9) **What is the worst thing anyone has said to you?** When people say, 'I'm tired too.'
- 10) **And the best?** You're still you and loved.

Extra questions:

- 11) **Where would you like to be now?** Anywhere but trapped in this body...
A hot sunny beach.
 - 12) **Tell us a joke/mantra/quote.** Hope, Faith and Courage.
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Optimum Health Clinic Material

Group member ██████████ has a copy of the Optimum Health Clinic Manual/Workbook from the 90-day programme (2012) with CDs and book to loan out free of charge. (Postage if required costs £5.00, or it can be handed over at a coffee meeting by arrangement.)

The approach is that ME/CFS/FM is a real physical illness, but that an awareness of thought patterns and certain techniques along with nutritional support can help to alleviate stressors to allow the body to heal. This is a behaviour/thoughts/lifestyle programme and does not contain information about the nutritional side of the clinic. Most people who have not done any of this work before are likely to find something of value in the programme. You can text [REDACTED] on [REDACTED] or send her an e-mail at [REDACTED].

WhatsApp Group for All Ages

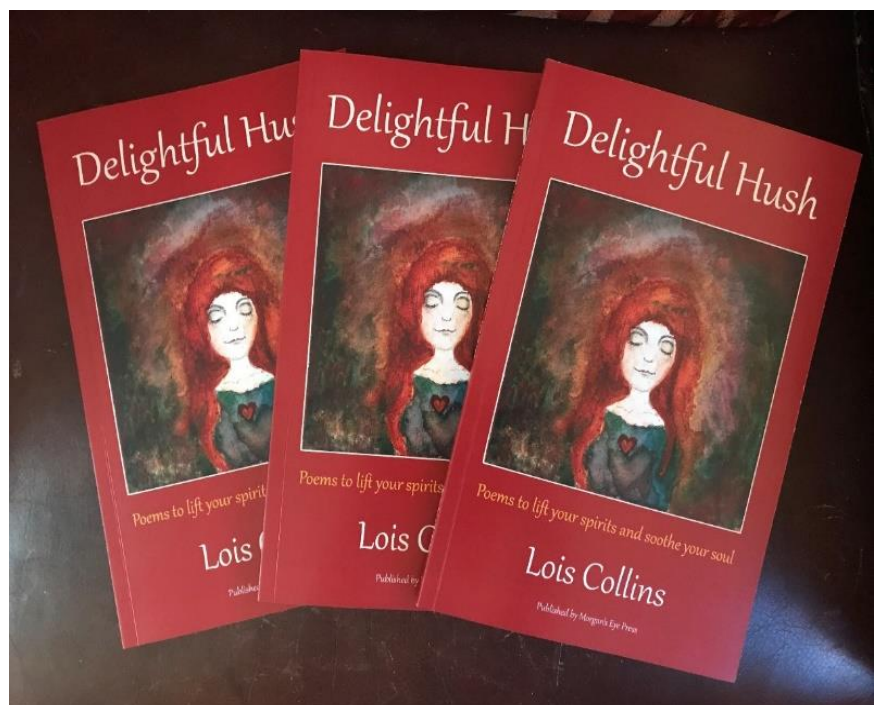
To complement our WhatsApp group for young adults with ME, we have set up a WhatsApp group for members of different ages. If you would like to join this group, please contact [REDACTED], our Membership Secretary, at [REDACTED].

What Our Members Are Doing

Done anything exciting, inspiring, interesting? Although ME does its best to make our lives miserable, this does not prevent us from trying to make our lives as fulfilling as we can. So do let us know what you're up to.

Why not buy a copy of [REDACTED], a splendid book of poetry and paintings for yourself or as a present for someone else? Get in touch her at [REDACTED].

[REDACTED] had a letter in the *London Review of Books* on 24 February 2022, on the definition of the word 'jollop' (yes, really).



Listening Line

The Listening Line is a support service provided by the Group to help you with the

emotional burden implicit in life with ME. [REDACTED] is a friendly person with previous experiences of helping people as a nurse. She has empathic ears and will be there to listen to you when you're feeling down or isolated and needing to talk to someone. Please bear in mind that she is not running a helpline which can tell you how to deal with benefit applications, emergencies or anything critical.

Like the rest of us, [REDACTED] is dealing with the challenges of having ME and therefore she might not be immediately available when you call her, but she will call you back as soon as she can. You only need to dial or send a text to our answerphone number [REDACTED], leave your name and a phone number and she will call you when she is available. Please be aware that she will not be able to answer your call after 8:00pm as she needs to rest. We hope this service can be of good value to you.

A Generous Donation

We are most grateful to the Kingston Charitable Foundation for their generous grant of £200, which will help pay for our annual subscription to Zoom. Our members now have easy access to our on-line meetings, merely by clicking on a single link or by keying in just one meeting ID and password. We wish the KCF all the best with their endeavours.

Annual General Meeting Report

We held our twenty-first Annual General Meeting on Saturday, 16 October on Zoom. [REDACTED] welcomed our members and asked them to introduce themselves. She mentioned apologies from [REDACTED], [REDACTED] and four other members. Thirteen members in total attended the meeting.

[REDACTED] listed our achievements, starting from mid-November 2020, and here are some of them:

- ★ We ran eight on-line social meetings per month: three for coffee, one for pub, two for mindfulness, one for crafting and one for silent reading. We started face-to-face coffee meetings parallel with the on-line ones when the lockdown was lifted in June, twice a month.
- ★ The on-line meetings allowed us to reach members who were usually housebound and therefore unable to attend our events, and they also helped us to keep maintain our activities during the lockdown.
- ★ Mindfulness, crafting and silent reading on-line meetings have been helpful for our members who are interested in quieter activities.
- ★ We are also supporting people with Long Covid, we now have three members with this condition.
- ★ We now have two groups in WhatsApp, one for young adults and the other for all members.
- ★ We promoted the results from our 2019 Survey among social care organisations, such as Enable Leisure and Culture in Wandsworth and Healthwatch in Richmond.

- ★ We met on-line for the ME Awareness week and the #MillionsMissing Day on 12 May. A substantial amount of information was displayed on our Facebook page, and photos from the event were published there and in our Twitter account.
- ★ We had a meeting with the Chronic Fatigue Service at Sutton Hospital, providing feedback in order to help them improve their treatment of the illness.
- ★ We supported two members via our Contingency Fund, giving a total of £150.00 in respect of issues related to GP letters for PIP and ESA applications and new devices to connect to our on-line meetings.
- ★ We supported two members, who successfully obtained their PIP.
- ★ The list of consultants with feedback in our e-mail bulletins has been helpful for some of our members.
- ★ We kept updated lists of wellbeing resources and friendly GPs.
- ★ We distributed a draft letter among our members to be e-mailed to their GPs, so they could be included in the priority level 6 for the Covid-19 vaccine, based on the ME Association's suggestion for people with ME.
- ★ We spread the word for the signing of petitions to release the new NICE Guidelines as soon as possible, and wrote to MPs in the main boroughs that the Group covers.
- ★ The Library has been updated with new books.

█████ talked about the on-line activities and plans, saying that we had run 91 on-line meetings in the past year. She thanked █████, █████, █████ and █████ for helping her to run some of them. She said that the aim was to rotate days of the week so people with a regular commitment wouldn't lose out, although we always would have a meeting on the fifth day of the month as usual. We had a small number of new attendees and we had reconnected with several members who were unable to attend face-to-face meetings. She said that almost 30 per cent of our members had attended an on-line meeting and a little under half of these currently attended regularly, as there were typically seven or eight people at a meeting, about eight at the coffee and pub meetings and six or seven at the quieter mindfulness, crafting and silent reading meetings.

█████ said that she had made contact with a number of different local ME groups looking for new on-line ideas, and realised that we had done more than many of them!

█████'s plan for the New Year is to offer an on-line group following the eight-session mindfulness programme described in the *Mindfulness for Health* book, which also comes as an audiobook (there is a review in the 2021/2 edition of our newsletter). She will e-mail the group with a proposal for feedback. This would be in addition to the current schedule.

█████ added that she was also very open to new ideas for on-line meetings. For example, she knew that on-line colouring clubs work and she could provide a set of drawings to colour (as downloads for people with printers or by post if not), but people would need to provide their own crayons or coloured pens. Members who are interested should get in touch by e-mail, or simply tell her at an on-line meeting if they would like her to try something else. She added that if anyone is interested in hosting any of these meetings (with support), please get in touch as holding eight meetings each month was challenging.

█████ then moved to Campaigning, saying that our planned local activity for #millionsmissing at Richmond fair was unfortunately cancelled for the second year running due to Covid. However, we did hold a #millionsmissing on-line coffee meeting on 12 May and took a screenshot of the 13 of us present, each holding up a sign showing how long we had been ill (the average there was 20 years) and we made a collage of photos of shoes for those who couldn't make the meeting. We posted these on our website, Facebook page, Twitter, millions missing sites, personal Facebook pages etc. The screenshot in particular got a lot of positive response.

█████ reported that we had engaged in the debate about Long Covid. █████ had been in direct contact with █████, the professor of infectious diseases who got Covid and initially wrote very supportive articles for the *BMJ* before he decided to replace evidence-based science in favour of the ‘think yourself better’ approach. We had reached out to people with Long Covid and were starting to welcome new members from that community.

█████ then said that we had joined a new group of local ME groups (called ME Local Network), which aims to share resources for campaigning and addressing benefit claim issues, and therefore we could benefit from it. She had attended a seminar on chronic illness, reporting on some research looking at why we were so ignored and under-represented compared with other disability groups. Two key points especially struck her. The first one was the language of fatigue being so inadequate and unhelpful — ‘I get tired too.’ She learnt that we needed to use the language of energy-limiting chronic illness (ELCI) and energy impairment to distinguish our illness from everyday tiredness. Members should start to use this language. The second point was the microaggression of the invalidation and disbelief faced every day by people with ME (and other chronic disabling invisible illnesses). We needed to avoid internalising this invalidation and to assert our lived experience. █████, who has ME, was doing a great job for us in pushing this agenda forward.

Regarding the Library, █████ said that she had updated and annotated the Library list and added some new books. Hopefully there will be a review of the new additions in the newsletter. She had identified a number of digital reference sources to help keep our reference material more up to date at minimum cost. She had started to collect and publish a ‘wellbeing’ resources list, using members’ experience of free or cheap on-line wellbeing resources.

Members can easily borrow physical items from the Library without cost. █████ will post them to your home with a stamped addressed return envelope, so you only need to get someone to take the item to a post box after you had finished with it!

█████ reported on the Group membership. She said that the membership stood at 168 with 18 new members joining us so far this year. The Group’s membership was 82 per cent female and 18 per cent male. The severity of our 80 members who returned the questionnaire last year was 11 (14 per cent) Mild, 34 (42 per cent) Moderate, 31 (39 per cent) Severe, and four (five per cent) Very Severe.

Sixteen (20 per cent) of these 80 members had reported their GP as being supportive and informed, 43 (54 per cent) supportive but uninformed, and 21 (26 per cent) non-supportive. In terms of stability of the illness, 19 (24 per cent) of these members have reported being stable, only six (seven per cent) improving, 31 (39 per cent) deteriorating, and 24 (30 per cent) fluctuating.

Only two (three per cent) of respondents said that they had received care from social services, and 27 (34 per cent) of members had a carer. However, it was important to remember that this was a sample representing 47 per cent of the total membership. Eight (44 per cent) of our new members had heard about us via on-line search, two (11 per cent) didn’t say how they found us, two (11 per cent) via a practitioner, four (22 per cent) via family or friends, and two (11 per cent) via another ME organisation.

In terms of areas, we had 39 members from Richmond, 34 from Kingston, 18 from Hounslow, 11 from Elmbridge, 13 from Merton, 11 from Wandsworth, four from Epsom and Ewell, three from Spelthorne, 11 from other areas of London such as Croydon, Ealing, Enfield, Kensington and Chelsea, Hammersmith and Fulham, Lewisham (two), Southwark, Sutton (two) and Westminster; 20 from other areas of the south of England, such as Berkshire, Buckinghamshire, Chichester, Dorking (three), Dorset, Dover, Guildford, Hampshire (three),

Hertfordshire, Reigate and Banstead (two), Runnymede (two), Salisbury, Wiltshire and Windsor; three from the Midlands (Derbyshire, Rugby and Leicestershire) and one from Abergavenny in Wales.

██████████ said that we had three new members with a diagnosis of Long Covid, both having joined us this year.

██████████ talked about our meeting with the Chronic Fatigue Service at Sutton Hospital, highlighting that our feedback has helped them to improve. It was good to know that Dr ██████████ was there to ensure enough funding for the continuation of the Service and that she wasn't altering or affecting their treatments by including more psychological therapies. He talked about a possible meeting with Healthwatch Richmond in November to find ways (if any) of helping some of our members in that borough, based on the results of our 2019 Survey and by talking to them directly. He said that we had kept in touch with Enable Leisure and Culture (part of the NHS) in Wandsworth after giving our ME presentation to them and hence they were handling people with ME with special care. He mentioned that we now had two WhatsApp groups where members with smartphones could share different information and express their feelings when needed.

██████████ highlighted the importance of the Contingency Fund in helping our members for their PIP, ESA, AA and other benefits application, as they could have more evidence supporting their cases by using any of the consultants mentioned in our e-mail bulletins. If you aren't receiving our e-mail bulletins, please give your most recent e-mail address to ██████████, our Membership Secretary and check you spam/junk folders, as they could be identified by your e-mail provider as a scam. Besides the consultants, our e-mail bulletins contain a list of helpful GPs, wellbeing resources, a link to access a Facebook page where you can ask and find information about benefits application, as well as much other relevant information.

██████████ moved to the Treasurer's report, noting that, so far, we had collected £279 from subscriptions, £297 from general donations, £0 from special donations, £0 from Waitrose, as due to the pandemic the company was supporting specific projects related to the Partnership and suggesting that probably we had to approach other organisations to obtain this kind of funds. We had collected £5 from gift aid and £26 from Amazon for a total of £606. He thanked all the members who have paid their subscription and given a bit more in donations and gift aid, and to everybody using the Amazon link on our website.

██████████ added that our expenses were led by postage with £555, mainly spent in second-class stamps for large and standard envelopes, followed by £150 given in two donations: £75 to the ME/CFS Biobank from the Cure ME Project based at the London School of Hygiene and Tropical Medicine, who were working tirelessly in finding a biomarker for the illness (and two of their team members, Dr ██████████ and ██████████, were part of the panel reviewing the new NICE Guidelines, using our testimonies as evidence to remove GET and CBT, so many thanks to them from all of us!), and the other £75 to ME Research UK, who were also working tirelessly with biomedical research finding the causes and consequences of the illness. We had spent £148 on subscriptions to Localgiving and Disability Rights UK, £137 on our website, telephone and social media, £100 from our Contingency Fund supporting two members (one of these members received £50 at the end of last year and again £50 this year and therefore it was reported £150 in our achievements). We had spent so far £74 in new books for the Library, £23 in stationery, £56 in sundries and £0 in printing and photocopying, but we were expecting a big bill from the printing workshop for our 2020 Christmas cards and three editions of the newsletters in 2021. In total, our expenses were £1243 and the total funds available in our account were £2982, with no liabilities owed to other organisations.

moved to the election of the committee but before he thanked, on behalf of the retiring committee, our helpers: for hosting some of our coffee meetings; for the medical students rota and for running our Twitter account (we had 1208 people/organisations following us and we follow 934; had handed over Twitter to Fernando); for running our Facebook page (it had 400 Likes and 406 followers; she did another sterling job again during the ME Awareness week this year); for running the Listening Line (she has handed over the Listening Line to); and with the recording machine for benefits assessments. announced the members of the new committee: , , , and . The general consensus among the 13 attendees was in favour of keeping this team for the next year! thanked for sharing her vast experience when it was needed, for his help with the minutes and our correspondence to other organisations, for the delivery of the greetings cards, her key input in our activities and campaigns and for supporting the membership, for our newsletters and helping host some of the coffee meetings, for joining the committee and being such a great help not only as our Membership Secretary and the new Line Listener, but also for helping hosting some of the meetings and other important tasks, and finally a big thank to for her great work organising and hosting the on-line social meetings and activities, for updating the Library, compiling a list of wellbeing resources, being in touch with other support groups, campaigning, attending seminars and thinking of new activities for the Group. The committee also thanked for organising and chairing our meetings, keeping the Treasury under control, supporting the committee and the membership, hosting the on-line pub meetings and helping with the face-to-face social meetings, among other tasks.

had her second-best AGM ever as, again, she didn't have to organise food, snacks and beverages for our members. She will be still smiling by the time you read these lines — and possibly until October 2022!

We had a good time and lots to celebrate in spite of another difficult year!

Contingency Fund

Please remember that you can apply for help from the Group Contingency Fund not only to pay for taxis or other travel expenses to see your GP/Consultant, but also to pay for their medical report and your medical information in the NHS system in order to support your benefits application. We have received lots of feedback about the difficulties of applying for PIP and other benefits; therefore, we consider that it is essential that you obtain an updated report from your GP, which usually costs between £25 and £50. Remember that this fund can also be used for such things as attending Group meet-ups and benefit assessments, or in a family emergency.

If you wish to apply for a payment from the fund, please contact any member of the Committee. The maximum you can claim is £50 per year and you will need to submit the receipts with the application form. If your circumstances are such that you need the money in advance because you're running low on funds or are needing more than £50, or if you aren't able to provide a receipt

with your application, please contact our Treasurer to discuss your situation before you apply.

Benefit Queries and Helplines

If you are thinking of applying for Employment and Support Allowance (ESA), Personal Independence Payment (PIP), Attendance Allowance (AA), Universal Credit (UC) or any other benefit that applies to your circumstances, please note that [REDACTED] ([REDACTED]) and [REDACTED] ([REDACTED]) are available for any question you may have regarding this matter. You should contact one or the other of them before you request your application form from the DWP, as once you do this you have only four weeks to complete it and you may need more time to do this or to obtain medical evidence to support your application. [REDACTED] and [REDACTED] can also send any queries on your behalf to [REDACTED], the benefits advisor from Disability Rights UK, who will attempt to answer them.

There is an excellent group on Facebook for anyone with ME who is applying for benefits — UK ME & Chronic Illness Benefits Advice, at https://www.facebook.com/groups/278260135547189/?multi_permaLinks=3943774848995681. If you don't have a Facebook account, please contact [REDACTED] or [REDACTED] and your query will be referred to this group.

The Action for ME's Welfare Advice and Support Service provides free confidential advice over the phone on welfare benefits, disability discrimination and employment issues to people affected by ME. It is open on Monday to Friday from 10.00am to 4.00pm. Call 0117 927 9551 or e-mail welfare@actionforme.org.uk.

The ME Association runs ME Connect. It provides support for people with ME and those who live with or care for them. It is open every day of the year between these times: 10.00am to 12.00 noon, 2.00pm to 4.00pm, 7.00pm to 9.00pm. The telephone number is 0844 576 5326. There is an e-mail contact at meconnect@meassociation.org.uk.

The Disability Law Service offers free advice on 020 7791 9800, and on-line advice can be obtained via its website <https://dls.org.uk/free-advice/online-advice/>.

Many Thanks!

We are very grateful to [REDACTED] for all the superb work she is doing to redesign and update the R+KME Group's web-site.

Richmond and Kingston ME Group Committee		
Chair	Vacant	
Secretary	Vacant	
Treasurer	██████████	████████████████████
Membership Secretary	██████████	██████████████████████████████
Project Coordinator	██████████	████████████████████
Committee Member and Group Library	██████████	████████████████████
Committee Member	██████████	██████████████████████████████
Social Secretary	██████████	████████████████████
Listening Line	██████████	██████████████████████████████
Twitter	██████████	████████████████████
Newsletter	██████████	██

The following members are not on the Committee but carry out important work for the Group.

Facebook	██████████	██████████████████████████████
Interview Tape Recorder	██████████	██

Group Website — <http://www.richmondandkingstonmegroup.org.uk>

Facebook — <http://www.facebook.com/pages/Richmond-and-Kingston-ME-Group>

Twitter — @randkmegroup

Disclaimer: While as a Group we prefer and endorse the term ME (Myalgic Encephalomyelitis), there may be times when articles printed from other sources contain the term Chronic Fatigue Syndrome. Any information in this newsletter must be checked by you, as we cannot accept responsibility for it. The use of alternative medicines or therapies is a matter for the individual. The views expressed are personal and not necessarily those of the Richmond and Kingston ME Group. Reference to any products or services is for information only, not an endorsement.

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