

# Richmond & Kingston

## ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

# NEWSLETTER

**No 1, 2024**

Inside — [REDACTED]'s Ten Questions — Annual General Meeting Report — GPs and ME — ME Online Workshop

## Visit Kew Gardens With the R+K ME Group!

The Richmond and Kingston ME Group has obtained membership of the Kew Gardens Community Scheme. This means that group members are able to enter the gardens *free of charge* during 2024. If you'd like to visit the gardens, please let us know by contacting us at [randkmegroup@yahoo.co.uk](mailto:randkmegroup@yahoo.co.uk). We'll send you more information and a code to show as you enter.

**When can you go?** You can visit at any time, on any day that the gardens are open for normal admissions. There is no need to pre-book. If you plan a visit but don't feel well enough that day, you can instead go on another day that suits you better.

**Anyone going with you?** If you have a necessary carer accompanying you, he or she can also enter free of charge, and doesn't need to use one of our code entries.

**Accessibility?** Kew Gardens have wheelchairs at each entrance, available to use during your visit. If you'd like to use one, just ask at the gate as you enter. Mobility scooters are also available, but they need to be pre-booked.

Helplines Information: See Page 15

If you visit Kew Gardens in March you'll see swathes of daffodils and crocuses in the Woodland Garden, the Natural Area and the Great Broad Walk borders.



And if you visit in April you'll see Kew's magnificent magnolias and bright cherry blossom, a treasure trove of tulips, and masses of breath-taking bluebells.



Group member [REDACTED] took advantage of the scheme in order to have a family visit to the gardens. Here's her description of the visit.

\* \* \*

Thank you for providing me with the Kew Gardens community access code. There was no problem getting into the site with the code.

I had hired a mobility scooter and it was there waiting for me at Brentford Gate. There were plenty of disabled parking bays at the entrance, so it was stress-free to park. The staff were very attentive and only a quick demonstration was required, in order to take charge of the vehicle! The paths were really accessible and there were clear signs to indicate ramp entrances, etc.

We went into the Palm house, which wasn't very accessible. There was a narrow, heavy door, which required one other person to prop it open, careful not to run over their toes! I think the building structure was quite old though. The routes were accessible inside, although very narrow. The Temperate House was very accessible, with automatic double doors, which was a welcome relief, with spacious indoor path routes.



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We had timed tickets for the Orchid display in the Princess of Wales Conservatory. We did have to queue for quite a while, despite the tickets, but I think it was just so busy, being a weekend. I decided to walk around the Orchids exhibition with my stick. I didn't think the display would be so lengthy, so in hindsight, I would have chosen to use a wheelchair to reduce the overall fatigue.

Overall, we had a lovely day, and my mum really enjoyed her sixty-fifth birthday at Kew Gardens.

## R+K ME Group AGM Report

We are pleased to present a report of the Richmond and Kingston ME Group's twenty-third Annual General Meeting, which was held online on 28 October 2023.

█████ started the meeting by welcoming everyone and reading our list of achievements. She said that considering that 2023 had been another difficult year, the Committee felt pleased with their achievements from the end of October 2022 until October 2023.

### Social Activities

We ran seven online social meetings per month: two for coffee, one for pub, two for

mindfulness, one for crafting and one for silent reading. We ran just one face-to-face coffee meeting per month as the turnout at them was still low compared to pre-pandemic times, and one face-to-face pub meeting in the year for the same reason.

The online meetings continued to be well attended and they had allowed us to extend our reach to members who were mainly housebound and therefore unable to attend our events. We celebrated our two hundred and fiftieth online meeting with a pub meeting on 24 February. Thanks to [REDACTED] and [REDACTED], we introduced a haiku group which had been very much enjoyed by members who attended, or who had been able to catch up using the videos of the sessions. Online meetings have also helped the Committee to maintain the group's other activities and to maintain contact with other organisations when needed.

We sent out over 350 greetings cards to members of the group. The closed e-mail network had 104 members. We had two groups in WhatsApp, one for young adults (with 13 members) and the other for everyone in the group (with 16 members). Facebook had 467 'likes' and 486 followers. Twitter had 1219 followers, and we follow 949 individuals or organisations.

### **Information Dissemination To External Parties**

Healthwatch in Kingston produced a survey for people with ME and Fibromyalgia, which we revised and which they presented to the Integrated Care Board (ICB) for the Royal Borough of Kingston in order to obtain more provisions.

We e-mailed the new NICE Guidelines and a helpful one-page leaflet, produced by the Sheffield ME and Fibromyalgia Group and Healthwatch Sheffield, showing the important highlights of these guidelines, to the ICB for Richmond and Kingston boroughs, which distributed them among their Primary Care Units in charge of liaising with GPs.

We gave edited versions of our newsletters to partner organisations and doctors interested in ME. We updated the various organisations hosting information about us on their websites in order to include all our online meetings, such as the ME Association, Hounslow Connect, Kingston Connect, amongst others.

Action for ME published an article about the group in their magazine, giving us more limelight within the broader ME community.

### **Disseminating Information Within the Group**

We provided in our e-mail bulletins a list of consultants with feedback, which has been helpful for some of our members. We continued to keep and share updated lists of wellbeing resources and friendly GPs. Our website had been improved and updated. We sent out three newsletters and four email bulletins during the year (we apologise for the missing newsletter, as we usually produce four).

### **Supporting Members**

We supported six members via our Contingency Fund, providing a total of £248 in issues related to GPs and consultants' letters for PIP applications, taxi journeys for medical consultations, and walking aids. We supported five members applying for PIP, another three members with printed hospital booklets, and one other member

with printed copies of the new NICE Guidelines. We also supported four members with Long Covid, three members with Fibromyalgia and two with Lyme Disease.

We reviewed the yearly follow-up letter for GPs from the Chronic Fatigue Service at the Malvern Centre in Sutton Hospital, in support of their implementation of the new NICE Guidelines.

### **Fundraising**

We joined the Charities Aid Foundation, where we can receive donations from everywhere in the world. The CAF validated us as an established charity in the country, after a thorough investigation of our records. We are pleased with this acknowledgement.

### **Campaigning**

Two members attended the #MillionsMissing ME Awareness protest at the Houses Parliament on 18 October 2022, and others watched the protest online. Photos of the event were published on our website and on Facebook. We met online for the ME Awareness week and the #MillionsMissing Day on 12 May. A substantial amount of information was displayed on our Facebook page.

We drew attention to a petition to Parliament to release funds for the implementation of the new NICE Guidelines.

We provided group members with a template for an e-mail to send to our MPs in order to complain about the new rules in the White Papers, and calling for the DWP to approach and assess people with ME and other invisible illnesses. We drew attention to the government's open consultation exercise that was organised to support people with ME.

We promoted DecodeME research among our membership, by way of our newsletter and our social media.

### **Group Meetings**

██████ reported that the online social programme had continued to be well attended over the past 12 months. We ran 91 online and 13 face-to-face meetings, that is, two gatherings each week.

One third of all our members attended a meeting either face-to-face or online, mostly coming to several meetings. Of these, three-quarters have attended more than one meeting (and some of those who have attended just once are very new to the group). In general, we saw meetings as quite a regular part of members' lives. About a quarter of all members came to online meetings and two-thirds of these attended online meetings without going to any face-to-face meetings. About one in seven members came to a face-to-face meeting. Half of them attended face-to-face meetings without attending any online meetings. But the overlap was very small. In other words, attendance showed us that online and face-to-face meetings are mostly reaching different members.

The attendance at face-to-face meetings doubled from three per meeting to six over the last year. Kingston All Saints Church was the most popular venue, but we had good attendance at all the venues we used, albeit with variation from meeting to

meeting. We ran our first post-Covid face-to-face pub meeting in Kingston in March, which five members attended.

█████ took the opportunity to thank our face-to-face hosts, █████, █████, █████ and █████, who had put in a lot of effort over the past 18 months to re-establish them.

For online meetings overall, attendance had an average of well over seven per meeting, but again different types of meeting attracted different members: only one-third of those who came to online meetings came to both chat and quieter meetings. In other words, the different types of online meeting were also attracting different members. The most consistently popular online meetings were the pub meetings, with an average of 12 members, and we had therefore focused our larger celebration meetings, such as the Christmas party, the two hundred and fiftieth online meeting, and ME awareness, on this format.

However, the various online meetings all continued to be well attended.

- ★ Mindfulness averaged almost eight people per meeting and had reached 15 per cent of members, plus some others making use of the links to do the sessions in their own time.
- ★ Coffee and chat averaged over seven per meeting.
- ★ Crafting and silent reading averaged over six members per meeting and had each reached almost 10 per cent of our members.

So again, many thanks to █████ and █████ for hosting the coffee and pub meetings. And finally, a big thank-you to █████ for proposing and running our latest online group, looking at haiku and how haiku could help us manage our ME; those of us attending are really enjoying it (six of us plus two virtual members). This group was running every three to four weeks. So, if you're free next time, she would strongly recommend that you give it a go.

## **Library**

█████ then moved to our Library Report, saying that having looked at our traditional resources, we had produced an annotated list of all our Library books and CDs in the last couple of years, and thanks to █████, we put this on the website (adding a form to make a Library request easier).

█████ also looked at the types of books previously borrowed, and informally surveyed members for their interests. On the basis of this, we bought some new books, she reviewed them for the newsletter and tried to promote more use of the Library — without making any impact whatsoever. She felt, therefore, that we now had better use for our money than to buy new books. However, the Library will remain open, entirely free to members, should anyone wanted to borrow any of our resources (it's usually new members who did this). █████ therefore had been looking more to digital resources. She said that we currently maintain a list of free or cheap well-being resources, which we published quarterly with the e-mail bulletins. Audiobooks were hard for us to offer but the Libby app allowed people to borrow these free of charge from a local Library and we publicised this on the website. And if we could develop more resources for the Library, she thought that we should now focus on digital resources.

## Membership

continued the meeting, talking about our membership. This was the year when we grew beyond 200 members! As a celebration of our growing numbers and geographical reach, we conferred Honorary Membership to a lady with ME who lives in Melbourne in Australia, becoming our two-hundredth member. She said that 48 people had expressed interest in joining us, and 26 new members had joined us in so far in 2023. We currently have 212 members in total.

	October 2023	October 2022
Active	201	178
Passive	11	9
<b>Total</b>	<b>212</b>	<b>187</b>
New	26	13
Female	180 (85%)	157 (84%)
Male	32 (15%)	30 (16%)

She moved to the membership analysis, saying that not all respondents answered every question and some ticked more than one box in a section; therefore, the percentages shown were related to the answers we received. We received 96 questionnaires by September 2023, compared with 75 returned by September 2022.

Of our members, 87 per cent told us that their ME was Moderate or Severe, a slight rise compared to 84 per cent last year.

ME Level	September 2023	September 2022
Mild	9%	11%
Moderate	48%	47%
Severe	39%	37%
Very severe	4%	5%

Fewer members reported that their GPs were supportive but uninformed compared to last year. However, although more were now reporting Supportive and Informed GPs, there were also more reporting Non-Supportive ones.

My GP is...	September 2023	September 2022
Supportive and informed	21%	16%
Supportive but uninformed	45%	55%
Non-supportive	25%	19%

Far fewer members this year reported that their ME was deteriorating, while significantly more reported that their illness was fluctuating.

From one year ago, my ME is...	September 2023	September 2022
Stable	17%	18%
Improving	9%	7%
Deteriorating	32%	52%
Fluctuating	42%	23%

Sadly, especially considering the level of illness of many of our members, out of 94 replies to the question, only one member (one per cent) reported receiving care from social services, while 23 (24 per cent) had a carer, often their spouse or other family member.

██████ also said that more members reported this year that they were seeing a consultant, but the rise was in those seeing private consultants, not NHS ones. It may be that more members felt able to start seeing new consultants than they did during and immediately after the Covid lockdown period.

<b>Am I seeing a consultant?</b>	<b>September 2023</b>	<b>September 2022</b>
Yes	28%	22%
NHS	13%	14%
Private	15%	8%
No	71%	76%

The ME Association had been an important way of reaching new members this year, while many other new members found us through online searches. Of 29 new members in the last 12 months, 22 told us they had found out about us through one of these two routes: ME Association — 11, Google/online search — 11. Others came via Action for ME — two, Facebook — one, Twitter — one, health practitioner — one, Kingston Council — one, and NHS CFS Service — one.

██████ continued by saying that in our most recent member renewal questionnaire, we had asked specifically for the first time about Fibromyalgia, Long Covid and Lyme Disease. Numbers were not yet completed, but we currently knew of 24 members who had Fibromyalgia, and 10 with Long Covid. Of the 24 members with Fibromyalgia, 21 also had Moderate or Severe ME. Of the 10 who had Long Covid, seven had previously had ME.

She then said that our members lived all over the place! Although we were the Richmond and Kingston ME Group, our name now related more to where our group began and from where it's organised. Of our 212 total membership, 81 (38 per cent) live in Richmond or Kingston, 61 (29 per cent) in other London boroughs, 40 (19 per cent) in other areas of Surrey, and 26 (12 per cent) in other parts of the UK. We have members from Scotland to the Isle of Wight and from Wales to Southend! There are 43 members in Richmond, 38 in Kingston; 18 in Hounslow; 15 in Wandsworth, 10 in Merton, three in Ealing, and 15 in other London boroughs. There are 40 members in Surrey, including 15 in Elmbridge, five in Spelthorne, four in Mole Valley, four in Epsom and Ewell, four in Sutton, three in Runnymede, and five elsewhere in the county. In the wider UK there are 26, including one in Oban in Scotland, two on the Isle of Wight, one in Monmouthshire in Wales, one in Southend, three in Hampshire, three in East Sussex, and 15 in other English counties. Abroad, there is one in Australia. Maybe we should consider renaming ourselves Richmond and Kingston International ME Group!

**Other Matters**

██████ continued the meeting, talking about our two sessions with Healthwatch in Kingston. They were providing helpful information for people with ME and



Fibromyalgia, and they were also talking to the borough's ICB in order to request more provisions for people with ME. Their website is <https://www.healthwatchkingston.org.uk/advice-and-information/2022-05-26/all-about-myalgic-encephalopathy-me-and-fibromyalgia-services>.

He highlighted the importance of the Contingency Fund in helping our members for their PIP, ESA, AA and other benefits applications, as they could have more evidence supporting their cases if they used the consultants mentioned in our e-mail bulletins. 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 other relevant information.

He thanked [REDACTED] for her work in setting up our new fundraising website with the Charities Aid Foundation. They requested a lot of information from the group and certified with HMRC that we were an established charity, although we don't belong to the Charity Commission of England and Wales as our turnover is under £5000 per year. We stopped using Localgiving after being with them for the last ten years (from 2013), thereby saving us more than £140 per year in subscriptions and fees.

He moved to the Treasurer's Report, noting that so far we had collected £364 from subscriptions and £476 from general donations. We had not received any special donations, nor anything from Waitrose because, due to the pandemic, the company was only supporting specific projects related to the Partnership. We're grateful that we received £500 from the People's Postcode Lottery Society Trust via Magic Little Grants from Localgiving in November 2022, to cover the expenses for our subscription to Zoom in order to help our members with tremors, and other difficulties caused by the illness, to access our online meetings with one click. We had collected £61 from gift aid and £28 from Amazon, towards a total of £929. He thanked the members who have paid their subscription and given a bit more in donations and gift aid, especially under the current circumstances where organisations are struggling to get funds (we collected a total of £542 in subscriptions and £820 in general donations, our best amounts so far in years). He also many thanked everybody who used the Amazon link on our website.

He continued by saying that our expenses were led so far by postage with £281, mainly spent in second-class stamps for large and standard envelopes, followed by £198 from the Contingency Fund supporting five of our members with their medical reports for their applications for PIP, taxi fares and mobility devices; £195 spent on telephone, website and social media; £180 for meetings and events (mainly on Zoom); £155 for general printing and photocopying; £70 for subscriptions to Disability Rights UK and ME Association; £56 for stationery; £30 for sundries; £7 for the Library. In total, our expenses were £1171 and the total funds available in our account were £2852, with no liabilities owed to other organisations.

[REDACTED] moved to the election of the Committee and he thanked, on behalf of the retiring one, members who had been kind enough to help the team: [REDACTED] for hosting some of our coffee meetings, [REDACTED] for meeting with medical students, [REDACTED] for running the haiku group, and [REDACTED] for helping with some technical advice with Word documents. He also thanked [REDACTED] for running our Facebook page so well in spite of her health challenges. Having named the 2022–23 Committee members, [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED], [REDACTED]

and [REDACTED], he asked for nominations for the 2023–24 Committee. The outgoing Committee members were proposed and seconded by the AGM attendees, thus keeping this team for forthcoming year! [REDACTED] thanked [REDACTED] for being our longest-lasting member of the Committee, [REDACTED] for the delivery of the greetings cards and her key input in our activities for supporting the membership, [REDACTED] for our newsletters and hosting the online coffee meetings, [REDACTED] for joining the team as our Membership Secretary and Webmaster, and [REDACTED] for her great work organising and hosting the online social meetings and activities, for updating the Library, compiling a list of wellbeing resources and thinking of new activities for the group to do. [REDACTED] also thanked [REDACTED], on behalf of the Committee, for organising and chairing our Committee meetings, keeping the Treasury under control, assembling the e-mail bulletins and doing other important tasks.

We then moved to our social meeting, which lasted until nearly five o'clock!

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## Group Meetings

The R+KME Group runs several types of online meetings for members. Each month we have two two-hour general coffee meetings, one starting at noon, the other at two o'clock in the afternoon; one 'pub' meeting starting at six o'clock in the evening; and two mindfulness meetings, one crafting meeting and one silent reading meeting, all starting at four o'clock in the afternoon. We have also started a monthly Haiku meeting, starting at half-past two. We're also running one 'face to face' meeting each month.

Details of the dates of all our meetings can be found on our website at <https://www.richmondandkingstonmegroup.org.uk/events-diary>. An e-mail reminder is circulated a day before each meeting, and this includes instructions on how to gain access to it. If you aren't receiving these reminders, or our e-mail bulletins, please check your spam/junk folders, as they do sometimes end up there.

If you would like to attend our meetings, contact [REDACTED] at [REDACTED] [REDACTED]. If you need better equipment in order to access our online meetings (a new PC, laptop, tablet or smartphone), we can assist you with £50 via our Contingency Fund. We are very grateful to Laura for all her hard work in coordinating these meetings.

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## Ten Questions

This time answered by [REDACTED].

- 1) **How long have you had ME?** Five years.
- 2) **What was the trigger that started it off?** After an evening meal with friends I woke up in the middle of the night with a loss of balance. Vertigo got better after six months, my energy didn't.
- 3) **What is the worst thing about having ME?** Isolation and loss of independence.

- 4) **Has anything good come of it?** A lot of time on my own to reflect on what is of value to me.
- 5) **What treatment (prescribed or alternative) has helped the most?** Not eating grains and dairy, somatic yoga and learning to feel all my emotions with the help of EFT (body tapping).
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Exercise. And too many supplements.
- 7) **What do you like doing on a good day?** Dance, sit or walk in the park, go to a live music event.
- 8) **Do you have any tips for getting through a bad day?** Nothing lasts forever, be as kind as possible to yourself.
- 9) **What is the worst thing anyone has said to you?** Have a good night's sleep, others have it worse.
- 10) **And the best?** Me too. Let me give you a hug. It is possible to recover fully.

Extra questions:

- 11) **Where would you like to be now?** On a beach in Australia.
- 12) **Tell us a joke/mantra/quote:** Make love of yourself perfect.

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## **ME/CFS, the NICE Guidelines and Some Obdurate GPs**

We reported in a previous newsletter on the government's 'interim delivery plan' on ME/CFS. The plan noted that many people with the illness reported 'dismissive attitudes' from some healthcare professionals and as a result felt stigmatised, disbelieved, unsupported and not treated equally. It added that some health professionals were not aware of the latest NICE Guidelines, and continued to hold misconceptions about the illness.

You can say that again! *Pulse*, the General Practitioners' magazine, asked GPs for their comments on this subject, and duly presented what some of them had to say on its website. The views of some GPs are, to put it lightly, dispiriting. Here we go...

I seriously think it's harmful/borderline abusive to diagnose kids with one of these symptom syndromes. And that's what these are, collections of symptoms with no test or treatment. Looks like the pressure groups have got to NHSE as they did with NICE. There's plenty of well considered thought out there including the FMAs (fellow travellers) original researchers suggesting the harms in medicalisation and naming of these symptom collections as illnesses.

Now it is true that people with ME/CFS display a wide variety of symptoms and the impact of the illness varies widely amongst us, but to dismiss it as a 'symptom syndrome' or 'symptom collection' — that is, a rag-bag of presumably unconnected symptoms — and not an actual illness really does ignore both the research-based

evidence that encouraged NICE to define ME/CFS as ‘a complex, chronic medical condition’, and the crucial symptoms, such as post-exertional malaise, that *are* common to everyone with the illness.

The term ‘medicalisation’ is another tell-tale clue of this GP’s school of thought: this means that someone isn’t actually physically ill, but merely imagines that he or she is; in other words that the debilitating problems that people with ME/CFS are experiencing are ‘all in our heads’. This GP also seemingly assumes that ‘pressure groups’ have unfairly and unjustifiably influenced the medical authorities, as if the latter are running scared of a bunch of unscientific rowdies who complain about being afflicted by imaginary illnesses, rather than being serious bodies that have spent a lot of time examining the evidence and, on this basis, radically changing the treatment of the condition.

And if graduated [sic] physical therapy is not recommended does the person a) lie still forever or b) have ungraduated physical therapy, for example, forced to run a marathon every day?

Neither! Graded (not ‘ungraduated’) Exercise Therapy, a course of steadily increasing physical activity as a means of attaining a full recovery, can be very useful and effective in respect of certain physical conditions, such as recovering from a broken limb, but is harmful for people with ME/CFS, which is why the revised NICE Guidelines firmly rule it out as a treatment. What is necessary is recognising that a person with ME/CFS has a certain amount of physical capability, and that trying to push beyond these limits is harmful.

So much for scientific evidence-based medicine. Let’s reprogramme all the doctors so they can medicalise and believe anything. When are we getting the homeopathy training? At least we can give patients something.

Here we have ‘medicalisation’ again. In the past, it was not that uncommon for people, especially women, with Parkinson’s Disease or Multiple Sclerosis to be diagnosed with ‘hysteria’. Was accepting these conditions as neurological illnesses a case of ‘medicalisation’? The now discredited analysis of ME/CFS as a psychological problem that could be cured with Cognitive Behavioural Therapy and GET led to practice that was in the first case misleading and in the second case harmful. Homeopathy is indeed unscientific quackery, but, unlike GET, will only hurt one’s wallet. Once again, one suspects a lack of familiarity with the revised NICE Guidelines.

As we are all so busy and barely managing the conditions that *do* have valid treatments would it not be better to concentrate our stretched resources on illnesses that we can help? The government should suggest ME-type patients go straight to self-help groups and online advice. Pretending we can help is demoralising for both the patients and the GPs and is gaslighting both groups

We all sympathise with GPs and their excessive workload. But apart from the fact that we actually do find self-help groups and advice on the Internet, this GP seems to have forgotten that we need to visit our GPs to obtain sick-notes, prescriptions and

other official documents if we are to obtain medicines and welfare benefits and to explain absences from work.

Hmm. CFS/ME. Diagnostic criteria — no international consensus. UK criteria published by NICE. Cause unknown. Pathology unknown. Prognosis unknown. Treatment unknown. It's a bit hard to see quite what we are to be educated about, really.

Well, there's the recent, radically revised NICE guidelines. As we have seen, these significantly change both the pathology and treatment, stating, firstly, that ME is a genuine illness — that is, not 'just in our heads' as the psychosocial school insisted (and indeed still insist) — that CBT is useful in dealing with the symptoms but no more, and that GET is harmful and not to be used.


Physical activities are good for ME and CFS. And working help [sic] their mental health.

Nobody is denying that physical activity *can* benefit *some* people with ME/CFS, and that in *some* cases working *can* help with our mental health. But, to cite the revised NICE Guidelines, 'people with ME/CFS, physical activity may make their symptoms worsen'. Once again, it is the matter of discovering our limits — how much physical and mental activity we are capable of doing without our exhausting ourselves — and managing our lives on a day-to-day basis within those limits; that is, the art of pacing.

More 'training' — will it never end?

Well, judging by the responses from the GPs' statements here, a training course that brought out the essence of the revised NICE Guidelines — that is, showing its analysis of the condition and the changes it recommends in respect of the treatment of the condition — would not go amiss, wouldn't it?

This is not to deny that there are many GPs who do their best to help people with ME/CFS, who are sympathetic to our plight, and who have taken to heart the recommendations of the revised NICE Guidelines. However, the medical world can be remarkably conservative when existing ideas and practices are challenged; Dr Joseph Lister's ideas about the vital need for the sterilisation of wounds and instruments in surgery met with considerable resistance from health professionals. One has sadly to conclude that those GPs cited above are content to stick by old, discredited dogmas in respect of both the analysis and the treatment of ME/CFS, rather than take on board the revised NICE Guidelines. Let us hope that at some point they will follow NICE and reconsider how they deal with our illness.



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## What Our Members Are Doing

Done anything exciting, inspiring, interesting? Although ME does its best to make our lives miserable, and the Corona Virus adds yet more botheration, 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.

████████ crocheted this tank top for her daughter, whilst ██████████ has been busy with her embroidery.



████████ has had an article, 'Isaac Deutscher and his Left-Wing Critics', published in *Critique*, Volume 53, no 4, which looks at the way this historian's often controversial ideas were assessed by his contemporaries.

## ME Online Workshop

Attend an online workshop this summer and contribute your experience and views to ME medical research planning.

Brighton and Sussex Medical School (BSMS) have asked if any of our members would be interested in attending one or more online workshops this summer. It's hoped that the workshops will contribute information for BSMS ME medical research funding proposals.

- ★ 4 June, in the afternoon: Clinical trial design in people with ME/CFS.
- ★ 26 June, in the afternoon: Drug repurposing in ME/CFS.
- ★ Later in the summer: ME/CFS research in underserved groups.

The workshops will be hosted by Harm van Marwijk, Professor of Primary Care at Brighton and Sussex Medical School, and Monica Bolton, a retired GP who recovered from severe ME and has spent the years since then campaigning for medical research into ME.

At the moment they are taking expressions of interest — you don't need definitely to say that you want to attend. If you think you even might like to attend any of these workshops, please message ██████ at ██████ indicating

which of them you're interested in. We'll make sure you receive a registration link much nearer the time.

**Underserved Groups:** The workshop on ME/CFS research in underserved groups includes people from *ethnic minorities, socially deprived communities and people with severe/very severe ME/CFS*. The date isn't yet fixed, but please do let Zena know if this is an area that interests you.

Monica Bolton is interested in connecting with people with ME/CFS from any ethnic minority for an e-mail exchange or zoom call with her. She is still planning the third workshop and would like input from people who may have direct experience of being disadvantaged by 'the system'. Please let [REDACTED] know at [REDACTED] if you can do this.

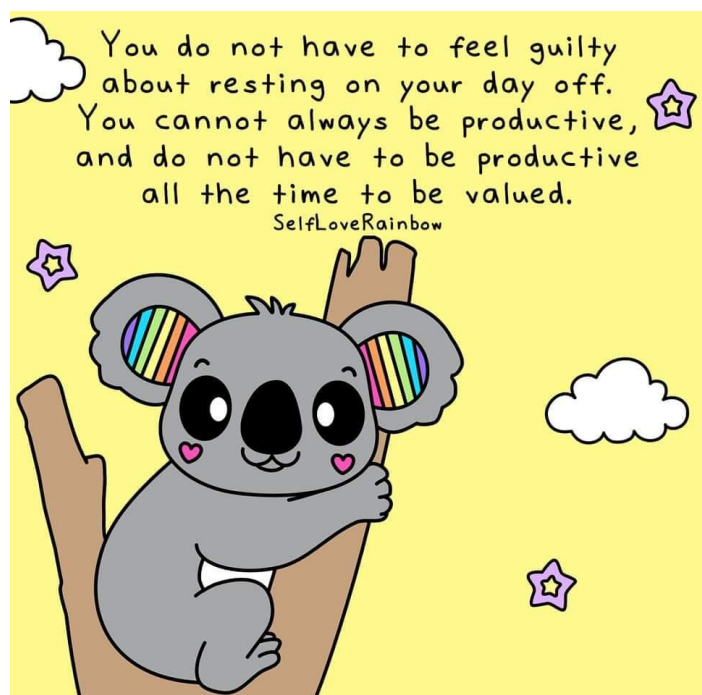
## Benefit Queries and Helplines

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 Ken Butler, the benefits advisor from Disability Rights UK, who will attempt to answer them.

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](mailto: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, or e-mail [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk).

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



Richmond and Kingston ME Group Committee		
Chair	Vacant	
Secretary	Vacant	
Treasurer	[REDACTED]	[REDACTED]
Membership Secretary	[REDACTED]	[REDACTED]
Committee Member and Group Library	[REDACTED]	[REDACTED]
Committee Member	[REDACTED]	[REDACTED]
Social Secretary	[REDACTED]	[REDACTED]
Twitter	[REDACTED]	[REDACTED]
Newsletter	[REDACTED]	[REDACTED]

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

Facebook	[REDACTED]	[REDACTED]
Project Coordinator	[REDACTED]	[REDACTED]
Interview Tape Recorder	[REDACTED]	[REDACTED]

**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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