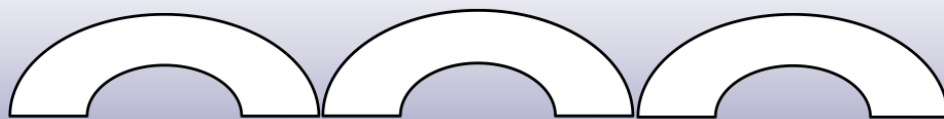


Richmond, Kingston & West London



ME Group

NEWSLETTER

No 1, 2026

Inside — Annual General Meeting Account — Fernando's Recovery Plan — Riding with the Disabled Association — And More

A Superb Day at the Kew Gardens Orchid Festival

Group members will be aware that thanks to the Community Access Scheme, we are able to visit Kew Gardens free of charge. Suzanne, one of our Committee members, went there with her partner Richard to visit the recent Orchid Festival. Here's what she saw.

* * *

Recently, I had the pleasure of visiting the Gardens with my stronger half, Richard, as part of our group's Community Access Scheme. We took advantage of the free entry available through this fantastic initiative, making the most of a sunny day to enjoy the much anticipated Orchid Festival. What follows is a recollection of the highlights and memorable moments from our outing.

Getting There and First Impressions: Our Orchid Festival tickets were booked for a 2:00pm entry, and the process of getting into the Gardens was completely straightforward. There were no hiccups or delays, which set a positive tone for the rest of our visit. The weather was simply glorious!

Exploring the Gardens and Princess of Wales Conservatory: After entering, we made

Visit Kew Gardens with the Group — Page 15

our way through the lush grounds towards the Princess of Wales Conservatory, home to the spectacular Orchid Festival display. The conservatory itself is a temperate space, also housing an impressive collection of cacti alongside the orchids. This juxtaposition made for an intriguing visit, as we admired the diversity of plant life in one place. The other amazing aspect was the creation of animals from natural materials, enhancing the display areas. Some people are just so talented!



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Community Access Scheme: Making Events More Inclusive: One of the real highlights of our day was being able to attend thanks to the Community Access Scheme. If you're considering a visit, I highly recommend checking out the events calendar — the Gardens host numerous events throughout the year, often with access schemes that make it easier for everyone to participate. It's well worth making the journey, regardless of the season. Also, wheelchairs and scooters are available to borrow from the entrances.

Interactions and Atmosphere: My interactions throughout the day were overwhelmingly positive. I had a few brief encounters with staff, all of whom were friendly and accommodating. Moreover, the public truly shone in their kindness and consideration. Not once did anyone complain about my use of a scooter; instead, they offered help opening doors, made space for me to pass, and even volunteered to take photos or patiently waited while I captured my own memories. It felt as though the wonderful weather had lifted everyone's spirits, bringing out the very best in people.



Final Thoughts and Recommendations: I sincerely hope you enjoy the photos I took and have the opportunity to experience the Gardens for yourself at some point during the year. Whether it's the Orchid Festival or one of the many other events, the Gardens are a treasure trove waiting to be explored. For those looking for a day out that combines natural beauty, community spirit, and inclusivity, I cannot recommend it highly enough. Many more pictures of the festival can be found on-line at <https://photos.app.goo.gl/fkcWXMLwd3YCho2d7>.

Me/ME

A Poem by Daniel

Losing myself to sleep,
While awake,
With each breath,
That I take,
So much so,
That I quake,
Not to return,
From this lake,
Which weighs me down,
Without break.
You say I'm lazy,
Must be fake,
But the lie,
That I make,
Is that I'm fine,
My mistake,
Now in bed,
Just a flake,
Of myself,

Without health,
Without wealth,
Without work,
Without a smirk,
On my face,
Without life,
By the grace,
Of a germ,
You cannot see,
That will not,
Let me free,
Myself,
From this chain,
For a life,
Without pain,
Just a shell,
Of who I was,
Just ME.

Riding for The Disabled Association

Jenny Mumford describes her adventures with the Riding for The Disabled Association

* * *

Before I became ill with ME/CFS, I'd always loved interacting with animals, especially horses. Once you have got over the initial fear of being in the company of a large and powerful animal, it is surprising how natural the interaction becomes, thus developing into a powerful partnership between 'man and beast'. I used to be, as a teenager, a stable-hand girl, mucking out horses, attending competition shows and getting lessons in return for labour. Life then got in the way, as I navigated a career in nursing and spent many unsociable hours caring for the sick. However, I never lost my love and drive for riding and being amongst horses.

Then when I fell ill with ME/CFS in 2018 and was unable to work any more, I found myself

yearning for ways to help stimulate and comfort me. This is where I came across the brilliant charity 'Riding for The Disabled Association' (RDA). Their main motto is enriching lives through horses and this rang very true with my previous experiences. My initial thoughts were, does my ME/CFS diagnosis qualify me to participate as a disabled rider? I was pleasantly surprised that the charity did in fact support people with chronic conditions. I decided to put my name down on their waiting list to become a participating rider at my local RDA branch in Epsom, Surrey.

I was ecstatic a few months later when I learnt that I had been allocated a slot to ride every Tuesday morning, for a 30 to 40-minute group lesson, led by an experienced session coach. Each session only costs £10 per ride, although this is due to rise soon to £20, to help keep the pony herd healthy and maintain revenue as a charity. I was initially concerned about whether I was physically capable of riding, obviously concerned about PEM and whether this once enjoyable activity would in fact become counterintuitive and no longer accessible to me. The team put me at ease straight away and went with how I was feeling on each given day. Some of the reasonable adjustments made to help keep PEM at bay were being able safely to dismount prematurely before the session ended if needed, riding aided with a volunteer holding onto the end of a lead rope, riding unassisted with a volunteer walking alongside me, occasionally needing to call in sick on the day in question, using a stick as an aid to help back up my tired legs and always being first to mount, helping to alleviate the autonomic dysfunction experienced during standing periods.



The Epsom RDA team is fantastic at adapting individual group sessions, with the intention of meeting each rider's bespoke needs. For example, the use of ramps and specially elevated mounting blocks, the use of colour-coordinated 'rainbow reins', particularly helpful for children and those with learning difficulties to help navigate where correctly to hold their reins, rope-led and unled sessions for those of higher ability, sensory games with cones/pole placement, a sensory grass track to reenact a countryside challenge and safety side-walkers for participants with epilepsy and at risk of seizures. Riding is available come rain or sun, with an indoor and outdoor schooling yard available all year round. There is also the option for riders to occasionally go off-site for a hack in the Horton Country Park, opposite the Epsom RDA site.

I currently ride a beautiful mare called Millie, who joined the herd in 2023. I've already formed a close relationship with her. She loves to receive hugs and is generally very lovable and responsive to human touch. Millie is 15 hands and three inches tall, making her one of the largest out of the herd. This makes her ideal for mainly adult and taller riders. On a 'very good day', the best feeling in the world is being able to trot on Millie and just feeling free and wild! Millie loves to stretch her legs and get her lungs going. Like us, she also has a chronic condition to contend with. Millie was diagnosed with asthma shortly after she joined the herd. Thankfully, this is kept mostly under control through a daily inhaler, a horse version of course! During times when Millie picks up an injury and is lame, I am still able to attend the RDA lesson. Instead, I focus on grooming Millie, getting the tatts out of her long mane and tail, preparing her lunch feed, checking her skin for bites/ticks and anything else untoward. I generally just enjoy spending quality time with my perfect princess!

Each year the RDA seeks to support over 39,000 disabled children and adults through activities including riding, carriage driving, and equine assisted programmes, such as 'Quiet Corners' and 'Tea with a Pony'. There are currently more than 450 RDA centres across the UK, from cities to rural areas. The warmth, rhythm and three-dimensional movement of the horse is transmitted through the rider's body and can help in relaxing tight muscles, strengthening core stability, reducing spasms, improving balance, posture and coordination. Like what you hear so far? Fancy the chance to ride or spend some therapeutic time with ponies? If yes, then to find your nearest group, you just need to enter your postcode into the find your local group directory via RDA Groups — Riding for the Disabled Association (RDA) Unfortunately the Epsom RDA site has temporarily paused their waiting list to participant riders, due to a high demand and a reduced livestock available. There are other RDA centres to explore, which may have a waiting list to join.

I am so grateful that this charity is available on my doorstep. The therapeutic role that horses play can never be overestimated. Through keeping personal goals/dreams alive, stored within our memory; this may one day prove to be your actual lived reality. I never thought I would ever be able to access horse riding again, because of the limitations attached to my disability. I was pleasantly proved very wrong. The power of the mind, imagination and keeping a sense of who we are, is certainly our Number One super strength!



AGM Report

Our twenty-fifth Annual General Meeting was held at 14.00 on 21 February 2026. The annual review and financial results were presented. We voted on the proposed revised Constitution and the election of the Committee. Dr Michelle Bull then gave a presentation entitled 'The Science of Energy in ME: Pacing, Wearables and the Nervous System', followed by a Q&A. A few hardy souls stayed on for a brief chat and the meeting closed at 16.10.

Annual Review for 2025

Our **group focus** is first and foremost on reducing the impact of ME on our members' lives. This year we have again extended the range of what we do, and also focused on building partnerships to help us achieve this aim.

The year of 2025 was one of growth. Membership grew from 237 to 329 with new members welcomed by Jenny and membership managed by Zena. Twenty-three new members came from our merger partnership with Network Mesh West London courtesy of Tony Golding and Pamela who had run that group for many years. The merger also resulted in a wonderful summer garden party hosted by Maggie and a new monthly late evening on-line Soirée hosted by Pamela. A second informal partnership with SELMESG arose from a very

generous donation they gave us early in the year, and you will be aware of Patricia de Wolfe's excellent benefits updates that we feature in our e-Bulletins.

We prioritise trying to support our members in three key ways.

I: Addressing the 'Aloneness' of ME with meetings and activities, newsletters and e-updates, our WhatsApp community and Google group, and Xmas and birthday cards.

Each month we are currently hosting four on-line chat meetings at different times of day thanks to Paul, Fernando and Pamela; four on-line quieter meetings thanks to Pamela, Elena and I; and four on-line mindful movement meetings thanks to Elena, who also ran an eight-week mindfulness course for us. Our first on-line meeting was in April 2020; this AGM is number 547. Our on-line Christmas party was hosted by Fernando and lasted a record breaking 4.5 hours!

We also host two face-to-face meetings each month thanks to Fernando, Jenny and Heather.

Paul produces two newsletters and Zena four e-updates a year, and through Heather, we send over 300 members birthday and Christmas cards; the Christmas card signing is quite an event for the whole Committee!

We have also started to post paper copies of our quarterly e-updates to members less able to access digital communications, thanks to Suzie (who also acts as a killer proof-reader). This means we now send something to our 'off-line' members eight times a year.

Our WhatsApp community now has 110 members — which is a third of the group — and is very active; the Google group which has 155 members is a quieter forum.

A major success this year was the launch of our WhatsApp community, which now has 17 chat subgroups — the new structure is key to keeping the number and content of messages received manageable for each participant. Thank you to Jenny and Zena, our WhatsApp admins.

This year we folded our Younger Members' WhatsApp group into our WhatsApp community, following which some of our younger members have joined additional chat groups. Also this year, Jenny has organised our first on-line meetings for younger members.

In addition, we have continued our Community membership of Kew Gardens meaning that members can visit for free. Amazingly, for the second year running, Kew Gardens gave us 20 Christmas at Kew tickets, which we allocated through a well over-subscribed ballot. Our members and their carers who went told us they had a wonderful time and sent us amazing photos of the event. Thanks to Zena for the organisation of this and to David Head for being there on the day for our Christmas at Kew group.

And most recently we have worked with artist Elaine Giles who was awarded a micro grant by Wandsworth London Borough of Culture to create a small on-line exhibition of portraits of borough residents living with ME/CFS. Eight of our Wandsworth members are involved.

II: Increasing the Availability of Information and Support (especially for the newly ill), particularly around pacing (through our website, leaflets, posters and our Visible and Tech-Bank projects).

As well as updating our website this year, we have expanded it to include a 'Pre-Diagnosis' section for people who are newly ill or awaiting diagnosis. This was developed by Zena in conjunction with Hillingdon ME/CFS service, which now includes a link to it with information for potential patients as soon as they are referred to the service by their GP, so they can access information about ME, advice on pacing and sources of support while they wait

for assessment and diagnosis (many thanks to Sophie at Hillingdon for having such an open 'can do' attitude in her work with us). We have a new pacing leaflet and group poster available if anyone can find places to use these.

Fran continues to provide us with a really informative Facebook presence. If you want to know what's happening now in the ME world, start here. Thank you Fran.

Our TechBank project aimed to allow people to try out some technology for free before committing to buying it; we had successes, most notably with noise-cancelling headphones, and some lemons (the 'sleep aid' didn't work for anyone!).

Our Visible project grew from the TechBank when a member donated their Visible 1 to it. Partnering with Visible Health and AfME resulted in our receiving 14 additional Visible devices and bands. We offer participating members a Visible device for three months and £10 subsidy towards Visible's £15 monthly fee for up to three months (prioritising members on benefits), with the aim of removing all possible barriers to trying it. We are currently on the second wave of the scheme — any member who would like to try Visible, please let us know. We will report back on our members' experience. Thanks to Zena for setting up and managing the TechBank and the Visible projects.

III: Seeking to Improve Services and Support for people with ME and Long Covid.

We mobilised members to write to their MPs about November's Westminster Hall debate and 30 did so! Three of the eleven non-MPs who attended were from our group and Jenny's story was featured by her MP during the debate.

Building and renewing our partnerships with local NHS providers of services to people with ME which are currently under review has seemed especially important this year.

We have renewed our relationship with the Sutton ME clinic, and formed a new relationship with Hillingdon clinic facilitated by Pamela, and we are participating in the Kingston Fibromyalgia Pathway Project. Zena coordinates many of our interactions with external bodies, and while many of the Committee are involved, particular thanks are due to Jenny who adds expertise and credibility in our dealings with medical services.

Leisha stepped back from the Committee mid-year where she had been responsible for creating the meeting schedule, sending out reminders, and other Committee business. Thanks to Leisha for everything she contributed to the group.

This year we have formally welcomed to the Committee Jenny (who manages our correspondence alongside her other roles), Suzie and Pamela (who also represents us at MELN). Over the year Zena has helped us develop and streamline our services. Heather and Paul continue to be a backbone of what we do. Many thanks to you all!

But 2025 was a year of growth; and it is great to be able to reach that many more people with ME, but the increase in membership and activities puts more pressure on the Committee and Committee Associates, all of whom except Zena have ME.

Can You Help? There are areas where it would be really helpful if we could get additional help. We do not currently have enough face-to-face meeting hosts; we would like hosts who can run meetings in their own local areas, especially in new locations. We provide guidance notes for suitable venues. Recently Kandice has offered to host a Wandsworth meeting, and Vick is hoping to begin to host meetings for us in Sutton later in 2026. We would love to have more members willing to host occasional or regular meetings.

If you are a creative soul, would you consider writing something for the newsletter; about your experience or activities or submit poems, pictures of your arts or crafts, or photos of local interest? Paul would be very grateful!

We also could benefit from for more admin support now we have more members and more activities; it feels to me that the Committee is currently operating very much at or maybe a little beyond our capacity.

We are very open to finding the right scale of task that you feel able to manage (and to adjust this if necessary). Recently we have seen a few members aiming for a return to work, which is wonderful. Is it possible that a regular commitment with the group would not only be helping the group, but could also be part of that journey?

If you'd be interested to explore what you might be able to offer the group, please drop me a line at lauracousins7@gmail.com, and we can see what is possible.

Treasurer's Report for 2025

Financially 2025 was a good year, and thanks to a pair of large one-off donations we ended in a stronger position. Year over year, our income rose by £1378 while expenditure was up £1162. We ended the year with a surplus of £1729.

Income: A) Windfall Income: South East London ME Support Group gave us a wonderfully generous £500 donation; and the merger of our group with Network Mesh West London resulted in a significant inflow of funds. B) Income Within Our Control: with this windfall income, we were able to delay 2026 membership renewals until this January. Your support is invaluable so a big thank you to everyone who has paid, and special thanks to some very generous members who help ensure that those who are unable to pay are not excluded from the group.

We started to get the full benefit of our membership of Easyfundraising, which brought in £560 in 2025. We have now raised over £1000 in less than two years. I can't believe how much I have raised through Easyfundraising personally given that I have bought nothing that I wouldn't otherwise have bought. When you buy on-line through Easyfundraising we get a donation at no extra cost to you (from groceries to car insurance, to holidays). Please have a look and see if you can support us in this way; you'll find the link at the bottom of our e-mails to you. We also still receive a smaller amount through Amazon on the same sort of scheme, so thanks to those of you supporting that. Subscriptions, donations and Easyfundraising/Amazon allow us to keep control of our destiny.

Expenditure: Overall we ask £5 per year for membership, although it costs us £10 per member to run this group. Costs rose this year for two reasons. Firstly, postage costs continue to rise and now account for over a third of our costs, partly courtesy of Royal Mail but also because we are now sending paper copies of our e-update to those members unable to access it electronically. Secondly, we have done more.

We spent more on printing, in colour and for off-line members: we developed and printed two new leaflets late last year, we printed two newsletters and four e-updates, and we are running a trial of colour printing which has made our printed materials much more attractive and user-friendly.

We invested in a subscription to Benefits and Work to enable our members to have access to key resources to aid in benefits applications, assessments and appeals.

The Visible project incurred costs of £250 and the TechBank project created postage costs of £100. We continued with our membership of Kew Gardens community scheme for which we paid £36 (and in addition to all the members visits, won another £680 worth of Christmas at Kew tickets!).

We spent £250 equipping our Committee with necessary technology; our group is 50

per cent larger than last year so the administrative burden is that much higher. We will continue to invest in technology that enables our hard-working Committee members to deliver services to you. Like most ME Groups, the main constraint to what we do is the sum total of volunteer energy available.

We spent £250 through our hardship fund. I'd like to take this opportunity to remind members in hardship that this fund exists to help members with doctor's letters for benefit applications, transportation to appointments, home repairs, etc. Drop me a line on lauracousins7@gmail.com to learn more or to request an application form.

Finally, I'd like to make a special mention of your Committee's commitment to saving money: Heather's remarkable ability to buy attractive birthday and Christmas cards extraordinarily cheaply; we now send about 600 cards year so this is a much valued skill, and Suzie and Paul's assiduous newsletter/e-update folding which saves us over £350 per year.

Vote on the Revised Constitution

Following our merger with Network MESH West London in the summer of 2025, the Committee felt that the name Richmond, Kingston & West London ME Group (sometimes shortened to R,K & WL ME Group) clearly indicated our main areas of operation and honoured the heritage of both groups. We started to use this in our communications from the summer and asked members if they would formally approve this name change in our Constitution at the AGM.

With our first two reminders about the AGM, we notified members of this proposed amendment and invited members to vote by e-mail if this were easier. A total of 31 members voted, all in favour, before the AGM. The AGM was attended by 46 members eligible to vote and all voted in favour. Removing duplicate votes, we had 63 members voting (19 per cent of our membership), all in favour of the name change and the new name was therefore formally adopted.

Election of Committee

The Committee resigned. All were standing for re-election and were re-elected. Your Committee are Laura, Heather, Jenny, Pamela, Paul, Suzie and Zena.

Dr Michelle Bull's Presentation and Q&A

After a short break we heard our guest speaker. **Dr Michelle Bull of Physios for ME** is a co-author of the excellent book *A Physiotherapist's Guide to Understanding and Managing ME/CFS*. Since qualifying as a chartered physiotherapist over 30 years ago, Michelle has worked in clinical and non-clinical roles with an emphasis on supported self-management of long-term conditions, including ME and Long Covid. She has extensive knowledge and experience of ME/CFS due to the condition affecting family members. Physios for ME are completely evidence driven, focused on practical ways to help people with ME manage and spread awareness of how physiotherapy must be adjusted to both help and avoid harm to them. Michelle's talk was entitled 'The Science of Energy in ME:



Pacing, Wearables and the Nervous System’, and she stayed to answer questions after her talk.

She started by briefly introducing the defining characteristics of ME and Long Covid with particular reference to post exertional malaise/post-exertional symptom exacerbation (PEM/PESE). For a physiotherapist, PEM presents special challenges; research has shown that people with ME have an abnormal physiological response to exertion and that deconditioning theory is unhelpful. So the principles of physiotherapy for people with ME need to respect PEM, do no harm and listen to lived experience, with activity level driven by perceived symptom levels.

Her main focus was on pacing. However, she highlighted the limited availability of research on this topic. She addressed the role of pacing to balance activity and improve how people with ME feel and introduced the ‘Four P’ model: plan, prioritise, pace but also pleasure. She introduced the steps involved in pacing and the skills required to do this, paying particular attention to the often neglected area of cognitive pacing. Research has shown cognitive exertion to be a common reason for exceeding the anaerobic threshold. She then provided some helpful suggestions for reducing cognitive load.

Michelle then addressed how wearables can help with pacing, looking first at heart-rate monitoring and describing benefits but also the potential downsides found in research. She also addressed HRV (heart-rate variability) monitoring. HRV has been found to be consistently lower in people with ME, where a high level suggests good fitness and stress resilience.

A Long Covid study found that HRV tracking can help people pace and prevent PEM. The Visible wearable has been shown to be helpful in predicting symptom flares. Overall heart-rate monitoring helps with ‘in the moment’ pacing decisions, while HRV is a trend marker of physiological strain and so gives a longer-term picture. But they are not a cure and their value in measuring cognitive exertion has not been shown.

She then turned to vagus nerve stimulation (VNS), which Physios for ME are currently researching. After a brief introduction to the vagus nerve and its role, she described the different ways in which it can be stimulated, the current clinical uses for this and some wearable devices on the market. She described the current research into the efficacy of this for Long Covid.

Building on this work, Physios for ME are involved in a piece of research looking at the impact of vagus nerve stimulation on people with ME, currently at the feasibility stage.

Michelle’s talk was very well received, described by members as, for example, ‘incredibly insightful’ and ‘very useful’. This report does not do justice to the breadth and depth of her presentation (and any errors in it are entirely mine!). A recording of her presentation is available on our website; I strongly recommend listening to it.

Fernando’s Health Improvement Path – Part II

Below we publish the second part of Fernando Campo’s Health Improvement Path. This part shows the improvements he has managed to achieve.

Group members should bear in my mind that this is Fernando's personal experience and that the Group Committee doesn't subscribe to all the therapies, supplements, foods, theories, views and opinions that are mentioned in this article. We understand that everybody is different and that medications, supplements, foods and treatments work in different ways for individuals and each of us has his or her own ways of dealing with the illness.

* * *

Healthy diet, what on earth is a healthy diet? A dietician from the NHS would say that it's an ingest of foods with a balanced combination of carbohydrates (high fibre starchy foods), protein, vegetables and fruits (five a day), dairy or alternatives, unsaturated oils and spreads in small amounts, and plenty of fluids (from six to eight glasses a day). This could include eating in a fast-food restaurant once or twice a week, as long as the meals there are balanced. A private dietician would give me a long list of good foods to eat, based on research behind them.

However, what I have found is that a healthy diet, in my case, is one containing healthy foods that my body could tolerate without giving me IBS, acidity, brain fog, bad reactions or taking my energy away. I had found that eating something healthy like eggs would give me nausea and take my energy away, unless they were organic and free-range from a particular supermarket, because the organic free-range eggs from another supermarket would make me feel ill. This is one aspect of where the complexity of this illness can be observed. We are all different with over a trillion micro-organisms living in our guts, like bacteria, virus, fungi and parasites, that are unique to us, and therefore we all need different types of foods from different providers. Basically, we have to become the researchers of our own bodies to know what they can take as fuel from each meal. This takes time, money and lots of energy: I know because I tried each food at least three times before labelling it as safe for me. I had noted the foods that would agree and disagree with my body in another article. By that time, eggs were one of the foods disagreeing with me until I tried them from a different supermarket.

Additionally, in my case, eating healthily meant having a lot of raw vegetables. If you could observe my plate, you would see it covered with celery, carrots, radishes, watercress, rocket, sauerkraut, cucumber and others, sparkled with olive oil, oregano and turmeric powders (turmeric is anti-inflammatory) and with a piece of cooked beef, pork or lamb on top of it.

Yet, as said before, everyone is different and there are people in our ME Group who can't eat celery, for example, as it's too strong for their digestive system to process. Everyone has to find out what's good for them and it's very important to listen to our bodies, paying careful attention to how we feel after eating anything.

I have lots of raw fruits in the morning, especially the blue dark ones like blueberries or black grapes, with almonds and nuts. I have scrambled eggs mixed with a portion of butter and garlic. Also, gluten-free pasta, noodles or rice with no sauces on them for dinner. It's good for me to eat clean (no fast-food and nothing processed), with no sugar or with a very low level of it and gluten-free. Once I became accustomed to eat without sugar, I struggled with any sweet, cake or pudding, because I would get a sugar rush and then crash. Once my body became stronger, I could tolerate everything more or less comfortably.

I would say that I don't eat my 'five a day', but my '10 to 12 a day' and here is the difference: four or five portions of fruits plus six or seven of vegetables. I eat the fruits and vegetables that give me energy, and avoid pineapple, lettuce and spinach, for example,

because they don't give me any, and I avoid lentils because they give me brain fog. Also, using olive oil on them is very important. I learnt by pure chance in a thermal spa centre in Baden Baden, Germany, that, according to some research carried out in Europe, olive oil helps the gut to absorb all nutrients from the foods we consume. I ordered there an orange juice, saw the waitress adding a tea-spoon of olive oil to it and asked why. Lucky me, the lady was French and could speak English, and — voila! — I got the answer.

Dark chocolate, with 90 or 100 per cent cocoa beans, was good in improving my mood and it was my reward every time I could conquer one of the steps planned in my recovery process. The amount of sugar in it is very small.

I consumed a jar of 200g of glutamine without exceeding 5g per day. In theory, glutamine helps to repair muscle tissue in the body, including the gut. However, as I didn't have a way of physically seeing the effect of this product in my body (whether it was healing me or causing me an additional problem), I only had one jar and felt an improvement afterwards. My concern was that maybe having too much of it could be counterproductive, as specified on the label.

Resting a Lot

Same question, what does that mean? For me, resting means 'sit or lie in bed, do nothing, think about nothing for a period of time and just breathe deeply'. The main element of resting for me was keeping my mind calm and clear. If the world was suddenly falling apart, stress would start to take my energy away and I had to try to get my mind calm and clear in any way I could; otherwise, I wouldn't be able to leave my bed. That was my main target in order to achieve a good rest and I learnt this after years of losing my energy on things that I couldn't control, or that I could control but needed more energy to deal with them, or that I could control, had the energy to deal with them but found them incredibly annoying, unnecessary and frustrating.

When I was feeling ill with severe ME, I wouldn't do anything at all and I would lie in bed or on the sofa the whole time, occasionally sending short texts to my friends from my smartphone and that's all (I feel grateful and lucky for smartphones, they made my life much easier and pleasant, allowing me to be in touch with friends, family and other ME patients from my bed/sofa, reducing my isolation). When my symptom levels were severe to moderate, I would do a light activity for 30 minutes and a heavy one for 10 minutes before resting for the remainder of the hour. When I was moderate to mild, I would do a light activity for 50 minutes, rest for 10 and then do a heavy activity for 20 or 30 minutes and rest for the remainder of the hour. It's basically like when I was a kid at primary school and engaged in an activity for 45 minutes and then had a 15 minutes break. However, in social gatherings I could spend from two to three hours being with other people on a good day, because this activity was very recharging for me. Of course, if my symptoms were severe, I wouldn't leave my house and see anyone. When I was feeling better, I could do an activity for an hour and rest for 10 minutes or do an activity for 90 minutes and rest for 15 minutes and so on.

Resting is not watching TV or texting or e-mailing constantly or reading or talking or thinking or, even worse, ruminating! When I was trying to rest for a few minutes I felt I had to become a sort of Tibetan monk in order to allow my body to recharge its batteries, preventing my brain from thinking about anything or remembering anything or ruminating with frustration about my health situation and personal circumstances.

Patients were taught how to do guided breathing and relaxation at the Lifestyle

Management Sessions at the SW London & Surrey CFS/ME Service and this was very helpful to me. However, not everyone can follow guided meditations or relaxation because some people have Aphantasia (and they don't know it!), meaning that they can't visualise and consequently can't follow these techniques. I believe that everyone can try finding a way of silencing their minds, thinking about nothing with their minds blank and focusing on their breathing for a few minutes in order to regain some energy.

Exercising

This is by far the most controversial topic for the ME/CFS community. We campaigned against Graded Exercise Therapy (GET) in the R&K ME Group, asking for its removal from the new NICE Guidelines 2021, as this therapy was causing more harm than good to many patients with the condition.

Now, the big question for me was: should I exercise? And, after losing all my muscles and nearly having a heart attack in 2015, the answer was a big straightforward Yes; otherwise, I wouldn't have lasted much longer breathing on this planet. I had tried walking and it was hard for me as my walking was already very limited. I tried cycling and found it less hard than walking but still hard, then swimming and it was horrendous. Then I remembered that I used to go to the gym when I was healthy and this one did the trick for me. I can understand why the NICE Guidelines 2021 on page 31 don't recommend anyone with ME to go to the gym without being overseen by an ME/CFS specialist team, because if you had never exercised there before you would need an induction from an instructor. This person would supervise you and probably ask you to do more and push yourself, leading you to a big relapse and deterioration of your ME. In my case, I didn't need any induction or supervision. I used to go when I could go, at a time when I could handle it, and I would do as much as I considered right, lifting the weight that I would consider right. Normally I wouldn't spend more than 30 minutes in total, having rests between the series of exercises. After the gym session, I would go to the steam room and sweat as much as I could for about 12 minutes in total, going inside for three to four minutes three times, resting for two minutes in between, to finalise the whole activity with a warm-water shower, but the last minute would be a shock given by freezing cold water. This shock would exacerbate all my Fibromyalgia pain and then it would ease it down, like a soother. However, I wouldn't have a cold-water shower if my ME symptoms were severe; otherwise, they would have got much worse causing strong PEM/PESE and a heavy relapse.

After trying the gym for many years, I reached an inflexion point when I couldn't stop exercising. If I had to stop, I would feel ill, and if I went there feeling insecure of getting PEM/PESE afterwards, I would actually leave feeling absolutely fine and better than before. At this moment I perfectly understood the big division among medical practitioners regarding this topic. Medical practitioners saying that a patient with ME should exercise were wrong and right at the same time and medical practitioners saying that a patient shouldn't exercise were also wrong and right at the same time. My view is that if we have severe symptoms then we shouldn't exercise at all, if we have moderate symptoms we could start to do whichever exercise we can cope with without causing PEM/PESE, and if we have mild symptoms then we should exercise, but only as the NICE Guidelines 2021 recommend on page 31, 'when we feel ready to progress our physical activity beyond our current activities of daily living or when we would like to incorporate physical activity or exercise into managing our ME/CFS'. Now, I can also tell from personal experience that medical practitioners

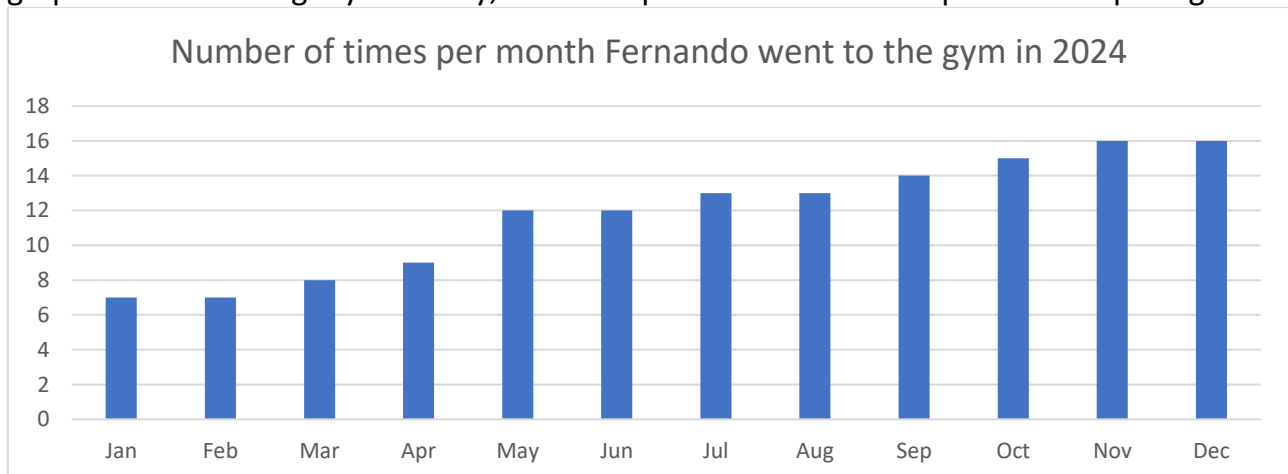
recommending GET are wrong at all times and under any circumstance and therefore I'm glad this therapy has been removed from the NICE guidelines. Patients must identify by themselves what exercise does well for their bodies and for how long, rather than a medical practitioner dictating a standard exercise for a standard period of time.

Going to steam rooms and saunas marked a bit difference to my body. I felt quite well after every session, in spite of all the discomfort caused by having a shower afterwards. I used a portable infrared sauna at home during the pandemic, which was also very effective. The advantage of this infrared sauna was that only my body had to be covered by it, leaving my head outside allowing me to breathe fresh air all the time. Steam rooms and saunas can be suffocating and therefore a bit difficult and tiring sometimes, but in my case, the cold-water shower would bring my energy back! An example of a portable infrared sauna can be seen in this link: www.uk-saunas.co.uk/portable-infrared-sauna-ept-002.html.

Pacing

What does pacing mean? For me, pacing means taking frequent rests and increasing the baseline of activities every three to four weeks. This depends on each stage of the illness as mentioned in the 'Resting a Lot' section. Although pacing wasn't mentioned to me by the two neurologists, it was a very important step in my recovery. I learnt to identify the activities that would take my energy at the Lifestyle Management Sessions at the SW London & Surrey CFS/ME Service and how to combine them with activities that would give me energy and with real rest. I built a baseline of activities that could be increased every three to four weeks in small steps, like 10 per cent or so. However, I believe I wasn't achieving much progress for many years because my diet was still the same.

I was a business analyst as a professional and I never imagined I would produce the graph below showing my recovery, which helps to illustrate the importance of pacing.



The graph shows the beauty of pacing reflected on the number of times I went to the gym each month in 2024. Once I found my baseline for an established exercise routine, I started with seven times in January, which would be every five days on average, roughly. I tried to increase the frequency at the end of the month, going every four days, but my body couldn't yet cope with this increase. However, I believed that keeping my healthy diet going would eventually heal my guts enough to increase the baseline later, which I did at the beginning of March. Then, in the middle of April I managed to go every three days for a total of nine times that month. You will see a big jump in May, when I could go every two to three days for a total of 12 times.

This increase was possible because, due to personal circumstances, I had to stop many activities I was involved with, like working for the R&KME Group's Committee and other volunteer jobs helping people, and concentrated only on eating healthily, resting a lot, exercising, looking after my daughter for a few hours per week and seeing friends when I could. I had the strong idea in my head that the more I could heal my guts the more activities I would be able to do. Additionally, I had my first glutathione injection of 2400mg in April and its effect was active two weeks later, in May (glutathione is an anti-oxidant and anti-inflammatory amino acid that helps to increase energy and detoxifies the liver). The pattern is quite clear from May and onwards reaching and keeping my final goal of going to the gym four times per week for a total of 16 times in December. Now it is January 2025 and my days of being stuck in bed are behind me. If I spend one or two hours having a nap, I feel refreshed. I still wake up in the mornings feeling a bit tired, heavy and dizzy, but somehow refreshed and not depleted as I used to be.

I also started to simulate going back to work for four hours, one day a week, at the end of November and now I can do it twice per week plus my four sessions at the gym. I haven't recovered to a point where I can do a full-time job yet, but it looks like I'm now on track to achieve this at some point in 2025. I think that tackling PEM/PESE is the most important task to do for anyone trying to recover from ME/CFS and Long Covid, because this is the symptom that disables us.

In summary, based on my experience, medical advice and inconclusive research, the theory about patients with ME/CFS having leaky intestines might not be correct and applicable for all of them, but they all could try eating healthily with foods that agree with their bodies, resting as much and as often as they can, exercising in any form when they can with safe routines that don't cause strong PEM/PESE, and pacing all their activities, in order to achieve a significant improvement with their illness and maybe, who knows, to cure it too. Health practitioners could help patients by acting as advisors of what they could do in their attempts to find ways of improving their resting, diet, pacing and exercising, following each case individually and taking into consideration their personal circumstances. I'm grateful for all the research being carried out by the CureME research team at the Royal School of Hygiene and Tropical Medicine, ME Research UK, Action for ME and the University of Edinburgh (DecodeME), others in the UK (with support of the ME Association) and in the rest of the world. Hippocrates of Kos (460–377 BCE), known as the father of modern medicine, used to say 'all disease begins in the gut', and it would be great if researchers could investigate more about the gut, as, to me, it seems to be an organic computerised reactor that may be more complex and sophisticated than our brains!

Kew Gardens

The RK&WL ME Group has subscribed to the Kew Gardens Community Scheme, and group members are eligible to enjoy free of charge the wonders of Kew Gardens. For more details and to make a booking, please send an e-mail to randkmegroup@yahoo.co.uk.

RK&WL ME Group Committee

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Committee Member	Jenny Mumford
Treasurer	Laura Cousins
Membership Secretary	Zena Carter
Committee Member and Group Library	Laura Cousins
Committee Member	Heather Abdelli
Committee Member	Pamela Phillips
Committee Member	Suzanne Williams
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The following Committee Associates are not on the Committee but carry out important work for the Group.

Facebook	Fran Christy
X (formerly Twitter) and Meeting Host	Fernando Campo Curiel
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