

# Richmond & Kingston

## ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

# NEWSLETTER

**No 1, 2021**

**Inside** — Heart-Rate Monitoring for Activity Management — Review of *Waiting For Superman* — [REDACTED]'s Ten Questions — And More...

# ME and Corona Virus Vaccination

The first phase of the government's Corona Virus vaccination scheme has been underway for some months, and is scheduled to be completed by the end of April 2021, by which time all people over the age of 50 will have been offered a vaccination.

Also eligible to receive a vaccination are people whose medical condition or other situation places them in Group 6 of the first phase's priority groups. This category covers people aged 16 years and above who have underlying health conditions which put them at a higher risk of serious disease and mortality, and this includes people with 'lowered immunity due to disease or treatment' or a 'neurological or muscle-wasting condition'. (This category also includes unpaid carers who receive carer's allowance or who are the main carer of an elderly or disabled person.)

There is, therefore, a good argument that people with ME should be included in Group 6, and the ME Association is providing a template of a letter

**Helplines Information: See Page 15**

which people with ME who feel that they should be in this group can suitably edit and sent to their GP if he or she has not invited them to be inoculated.

The template outlines various reasons why people with ME should be able to obtain a vaccination. The Joint Committee on Vaccination and Immunisation's *Green Book* guidance considers that people with a chronic neurological disease have an underlying health condition that places them in Group 6. Although the *Green Book* does not specifically list ME as a named example of a neurological disease, the guidance makes it clear that the examples given are not intended to be exhaustive, and the template states that 'the prescriber [that is, the GP] should apply clinical judgement to take into account the risk of COVID-19 exacerbating any underlying disease that a patient may have, as well as the risk of serious illness from COVID-19 itself'. The template then notes that various medical institutions, including the World Health Organisation and NHS England, recognise ME as a long-term neurological condition.

The template states that patient evidence to the MEA indicates that almost everyone with ME who has caught the virus has had a significant and/or prolonged relapse. 'This', it continues 'is not surprising given the considerable degree of clinical overlap between ME/CFS and Long Covid.' It advises that the MEA has confirmed that people with ME are being included in Group 6 by other GPs, Corona Virus vaccination centres, and various Clinical Commissioning Groups across the UK.

The template is available as a Word file at <https://meassociation.org.uk/wp-content/uploads/ME-Association-Covid-Vaccine-Priority-Template-Letter-GPs-V5-19.03.21.docx>.

If your GP has declined to place you within Group 6, you should approach your local CCG. The MEA has produced a template of a letter that can be suitably edited and sent to your CCG to see if it is allowing the necessary clinical judgement to take place. It is available as a Word file at <https://meassociation.org.uk/wp-content/uploads/ME-Association-Covid-Vaccine-Priority-Template-Letter-CCGs-V1-19.03.21>. Your local CCG can be found via this website: <https://www.nhs.uk/Service-Search/other-services/Clinical%20Commissioning%20Group/LocationSearch/1>.

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## **Book Review: *Waiting for Superman***

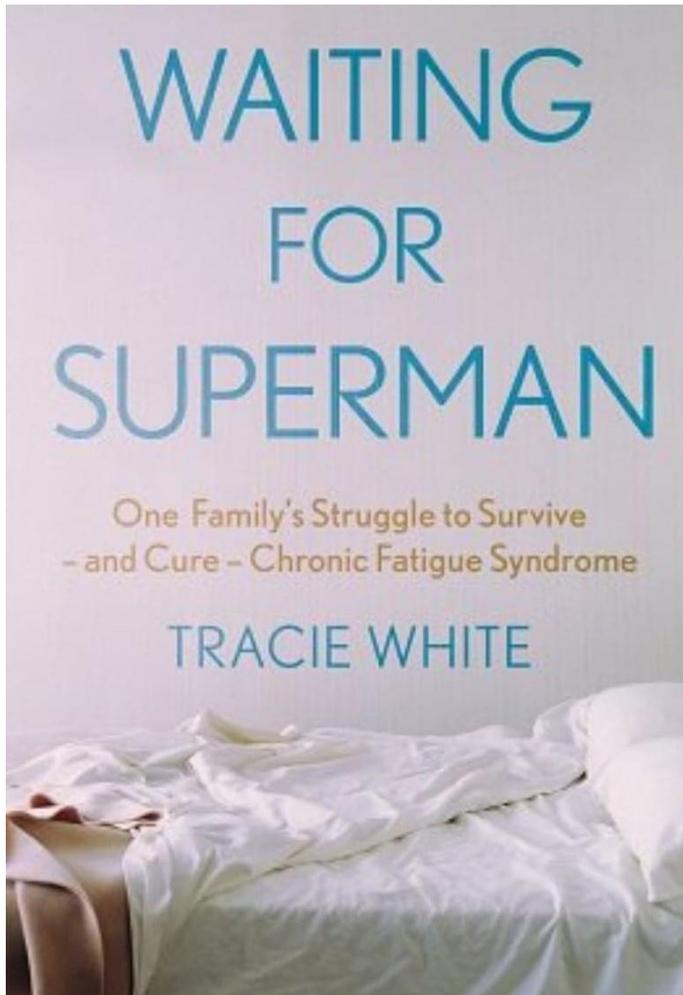
██████████ reviews Tracie White, *Waiting for Superman: One Family's Struggle to Survive — and Cure — Chronic Fatigue Syndrome* (Allen and Unwin, pp 240, £12.99)

\* \* \*

Tracie White wrote this book to raise awareness of ME/CFS and to bring hope to people with ME. It tells the story of Whitney Dafoe, who has severe

ME, and his father Professor Ron Davis, who has turned from a prestigious career as an innovator in biotechnology and molecular genetics to focus on searching for a cure for his son. Tracie White works as a science writer in the communications department of Stanford Medical School, part of the University where Ron Davis works.

The book is written as an unfolding story of her investigation into Whitney and Ron and ME/CFS; she is very much part of the book, perhaps more than



I liked. This is very much a human interest story, written as a series of snapshots of Whitney interspersed with the other sections about ME/CFS, the outbreak of ME at Incline Village that was dismissed as hysteria (the US equivalent of the Royal Free outbreak), other people with ME such as Laura Hillenbrand (who has described her doctors' approach as 'arrogance paired with ignorance'), and the progress of Ron's research. This style reflects the limited access to Whitney, who is mostly too ill to see people and never able to see anyone for long. It also makes the story easier to absorb, if harder to get the overall picture.

The book starts in 2015, when Whitney, then 31 years old, had been bedridden for three years. She makes the severity of his illness and the impact on his life

very clear, constantly contrasting his earlier life as a photographer and 'adventurer' with his drastically reduced circumstances with ME. She writes evocatively about how his family's lives have been transformed and documents the medical gaslighting Whitney suffered as they have searched for treatments that might help.

The 'Superman' of the title is Ron Davis, whose fascinating backstory she describes (from overcoming constant illness as a child, growing up in a family that prized physical strength, being seen as an under-achiever, to creating a new rocket fuel at 14, and being part of the launch of the Human Genome Project). Since Whitney became ill, Ron has swapped genomics research for spearheading a drive into finding a cure for ME. She describes his struggles for funding, the fragmentary nature of research findings into

ME/CFS, and the eventual acceptance in the US that this is a biomedical, rather than psychiatric, disease. She implies that Ron has discovered a biomarker for ME, but my understanding is that the nanoneedle is not yet that (and progress has unfortunately been hugely hampered over the last year by lockdowns in the US and in China). But he certainly is finding increasing evidence that there is ‘something in the blood’ of PWME, which is a big step forward.

Meanwhile, and since the discovery of the positive effect of Ativan and then Abilify, Whitney’s situation has become a little brighter and he can now communicate more.

What I really liked is that the book is extremely readable. Tracie White is a science journalist (though there is not much science in the book). She is always clear and carries you along on her story; it is very hard to put down. And despite detailing the dreadful circumstances of Whitney’s life, this somehow avoids becoming a traumatic read. There is an underlying optimism in the book.

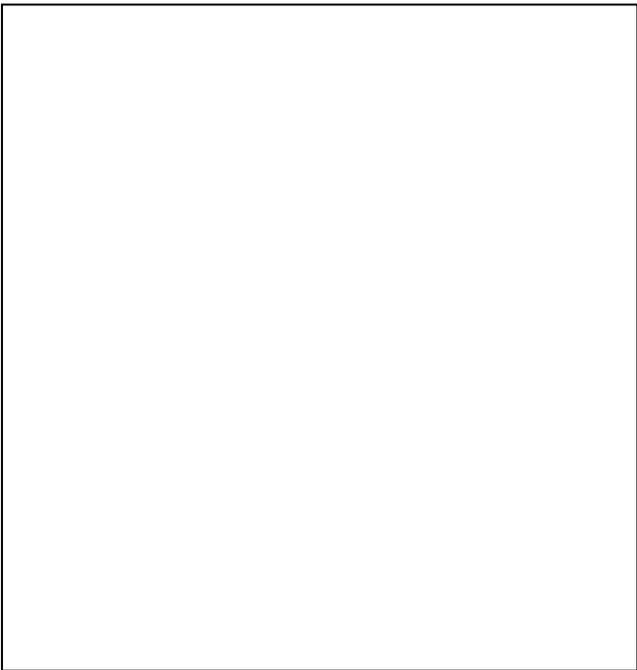
I think you will want to read it.

**██████████ – Our New  
Committee Member**

Hi, I’m ████████. I’m a very new member of the Committee. In fact, I only attended my first Committee meeting at the beginning of February 2021! I’m 28 years old and previously worked as an Adult Nurse before I became unwell. Health and Wellbeing are topics which I am very passionate about.

I was diagnosed with ME/CFS in August 2019, but had the classic symptoms for about a year prior to diagnosis. Being newly diagnosed, as a young adult with a chronic condition, was a very lonely and frustrating time. Knowing that there were no current curative treatments available to our community, I began to feel very isolated.

However, in October 2019, I came across this wonderful group and decided to join up. Subsequently, members have been nothing short of fantastic, in helping to support me and making me feel so welcome within the group setting. I decided I want-



ed to give something back as a thank you to the group as a whole. I am therefore honoured to be welcomed on to the Committee, as Membership Secretary in the making. Special thanks to [REDACTED] for assisting with the handover of this role. I look forward to helping expand and shape our special group over the coming months and years hopefully!

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## Ten Questions

### This Time Answered By [REDACTED]

1. **How long have you had ME?** Officially, just under two years now.
2. **What was the trigger that started it off?** I had a likely viral infection, but I continued to work and push through regardless.
3. **What is the worst thing about having ME?** I miss the active old me who would crave spin class and long-distance running. I also dislike how this condition robs us of the control to do as we please.
4. **Has anything good come of it?** I have learnt to appreciate the little things in life. I also value the relationships I have with friends/family more. I have more empathy towards other people with disabilities, particularly the impact this has on the working-age person.
5. **What treatment (prescribed or alternative) has helped the most?** Strict pacing has been the most beneficial advice so far. I also believe that having a positive outlook helps with learning to cope with chronic illness. I take Naproxen for muscle/joint pain, which is sometimes effective.
6. **And which was the most useless or did the most harm (to you or your pocket)?** CBT in a group environment via Zoom with no individualised care aspects.
7. **What do you like doing on a good day?** I enjoy walking a short distance (when I can) and sitting in the sun with a hot flask of tea! I also love chatting with friends and eating yummy foods.
8. **Do you have any tips for getting through a bad day?** I try to remember how I have felt on my good days and envisage this within my mind as something to look forward to again soon.
9. **What is the worst thing anyone has said to you?** 'It will get better in a year or two, you're only young so you will just get over it.'
10. **And the best?** My mum wrote in my last birthday card: 'Well done for coping so well, living with ME.'
11. **Where would you like to be now?** I wouldn't mind a nice holiday break somewhere — post-pandemic of course!
12. **Tell us a joke/mantra/quote?** 'How beautiful is it to find someone who asks for nothing but your company.'

## **Group E-Mails**

Some members have told us that they haven't been receiving our Group e-mails in their in-box.

Please check your 'spam' and 'junk' folders, as it's quite possible that our e-mails have been directed there automatically by your Internet Service Provider.

## **A Consultation with Dr Jan Coebergh**

We present below a report by one of Group members of a consultation with Dr Jan Coebergh.

\* \* \*

I was referred to the consultant Dr Jan Coebergh via my GP on the second attempt of asking for this referral to be made. The consultation took place four weeks later at Cobham Day Hospital, which forms a clinic attached to Ashford and St Peter's Hospitals NHS Trust. Dr Coebergh is a Consultant Neurologist who works as the Clinical Lead for Neuroscience at St Peter's NHS Foundation Trust. He is also the Honorary Consultant Neurologist at St George's and Royal Surrey Hospitals. In addition, he teaches students at St George's Medical School.

During the consultation with Dr Coebergh, I felt very much at ease. He was polite and courteous whilst introducing himself. I was invited to sit down and make myself comfortable. Firstly, a thorough history was taken and written down carefully. I felt he was fully attentive and listened very carefully to my symptoms and concerns. A full neurological exam from head to toe was then performed. Informed consent was given and my dignity was maintained at all times. I felt that Dr Coebergh was particularly interested in the finer details of the exam to make sure no area was missed. This reassured me greatly because often our symptoms are not explored deeply enough, as we all know!

After completion of the neurological exam, Dr Coebergh invited me to sit down once again to discuss his findings and plan of action. The plan was explained to me very clearly. I was asked if there was anything else that I wanted to raise with him. I didn't feel rushed or that I was wasting his time, as we can feel sometimes with other consultants. I was informed that my GP would be written to, detailing our discussion and planned tests to be performed. I was told to wait to receive the letters inviting me to attend the scheduled

tests. I was amazed at how quickly I received my appointment letter through the post, this was only five weeks later.

Overall, I would definitely recommend future members to ask their GP to be referred to Dr Coebergh directly, regarding neurological complaints. He is very personable and extremely knowledgeable in his line of work. He is also quick when referring to other departments and arranging tests for his patients. It is not often that we find a consultant who has good interpersonal communication skills, and therefore I was pleasantly surprised!

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## **The Sutton ME/CFS Facility**

We present below a report by one of our Group members of the ME/CFS facility at Sutton Hospital.

\* \* \*

On referral to this service in 2019, I was firstly invited to attend Sutton's 'First Steps' education seminar. This provided a very brief outline of the medical understanding of ME/CFS, the biopsychosocial model, and an introduction to activity management. I was then given a list to complete before the seminar ended. This list gave me the opportunity to opt into either one-to-one Cognitive Behavioural Therapy, one-to-one Graded Exercise Therapy, one-to-one Nurse Specialist session, or the 'Taking Strides' six-week group education programme. It is worth pointing out that the waiting list for one-to-one sessions was up to ten months long. The waiting list for the group programme with 15 other members had only a four months' wait. My decision was therefore motivated by the waiting list constraints rather than my sole preference.

The 'Taking Strides' six-week group programme commenced via the Zoom platform because of the coronavirus pandemic. The sessions covered a range of topics including the biopsychosocial model, medical understanding, activity management, calculating activity baselines, sleep, value-based goal-setting, challenging thoughts/emotions, exercise and increasing activity, central sensitisation, setback management and long-term ME/CFS self-management. Due to the sessions all being conducted via Zoom, I found the whole process very impersonal. We were told to remain on mute for the whole session time, and, if we wanted to ask a question, to use the chat function. Due to the technological constraints of buffering and signal problems, some of the verbal communication was lost. This caused me a great deal of frustration and increased my stress levels. Trying to build a rapport with 15 other computer faces who I couldn't see in person was for me personally unachievable.

I found that the medical understanding of ME/CFS was rushed and not explored in any great detail. The activity management section was, however,

useful to explore, and the activity charts, once filled in, helped with general daily pacing. It was useful to find out from other group members during organised breakout rooms the things that helped them with the daily grind of living with ME/CFS. In the third session, I didn't understand the purpose of setting out value-based goals. Due to the very nature of ME/CFS, the future is very much unknown!

Overall, the sessions were informative in general, but they lacked any individualised approach to symptom management. Looking forward, I would have found future one-to-one sessions after the six-week group programme to be more beneficial personally. The constraints on waiting list times prevented the service from being able to adopt a more person-centred approach. I did, however, approach the service lead after completion of the programme, stating my disapproval that there were no further individual sessions on offer. Due to my perseverance, I was offered one individual session with the Clinical Nurse Specialist and then with the OT, both via Zoom. I found these two sessions extremely helpful because I felt my individual struggles were finally being properly addressed. My personal activity charts were then explored in detail and the relevant pacing advice was quite rightly given to me. I do worry that those who are less assertive may not be getting the individual help that they deserve. This is a major concern of mine, and it is something which needs feeding back to all relevant agencies.

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## **Pacing by Numbers**

This article, by Dr Bruce Campbell, the author of *Managing Chronic Fatigue Syndrome and Fibromyalgia*, considers that the core aspect of successful management of ME/CFS is pacing, which involves finding and staying within the limits imposed by the illness. By pacing, it's possible to avoid the intensification of symptoms, or post-exertional malaise (PEM), and it can increase your chances for improvement.

### **The Anaerobic Threshold**

The anaerobic threshold (AT) is the heart rate beyond which we draw on energy reserves we don't have, triggering post-exertional malaise. The threshold is often between 50 and 60 per cent of a person's maximum heart rate.

Maximum heart rate is often calculated as 220 minus one's age. So a person who is 50 years old may have an anaerobic threshold between 85 and 102 beats per minute. (There are detailed calculations at the end of the article.)

A study in 2010 suggested that a slightly different formula is appropriate for women. In this new approach, maximum heart rate is calculated as 206 minus 88 per cent of age. With this formula, a woman who is 50 years old

would likely have an AT between 81 and 97. These two formulas suggest a range within which your individual AT may fall.

### **Calculating the Threshold**

There are several ways to determine your AT. Some people report having found theirs by taking a stress test on a treadmill. These tests are offered in some doctors' offices and in many hospitals and other healthcare facilities. Other people have used telephone consultations with the exercise physiologists at Workwell Foundation in California. In these cases, the consultant estimates the threshold using a log kept by patients of their baseline heart rate and heart rate when active.

I used the third way, observing my pulse in my wrist and noting what rate triggered an intensification of my symptoms. Even if you use either of the above two methods, you may need to do something similar to what I did, experimenting to find how your symptoms respond to activity, and using your experience to find the heart rate that triggers PEM.

The principle to remember is *your* AT is the heart rate beyond which you trigger post-exertional malaise (PEM).

### **The Benefits of Monitoring Heart Rate**

Once you know your threshold, you can monitor yourself to discover when you are beyond your AT. One way to track your heart rate is to count the beats, as I did, but other people use a heart-rate monitor, an inexpensive device available for \$20 and upwards. Monitoring heart rate has at least five benefits.

**It Helps Define a Safe Activity Level:** In the words of one person bed-bound with ME/CFS:

I craved a boundary, something I could see or touch that would tell me what was too much. My heart-rate monitor is drawing my boundaries for me. When I can manage to get up and move around, but keep my heart rate below 105 beats per minute [that is, her AT], then I know I am safe to continue to do so.

**It Brings Awareness:** Wearing a monitor often leads to recognition of previously unknown limits. In the words of one person: 'Just getting the heart-rate monitor was a huge eye opener for me... Everything put me over the threshold!' Another said that she was surprised at some of the things that put her over her threshold, including many social activities, such as talking on the telephone, eating some food, watching news on TV, and repetitive motions such as chopping vegetables. And a third commented: 'It was quite shocking to find that I operated routinely above my AT.'

**It Provides Advance Warning:** Some heart-rate monitors have an alarm

that you can set to sound when your heart rate nears your limit, giving you time to change what you're doing and avoid a crash. As one person says: 'We set my monitor to alarm when I reached a bit below my anaerobic threshold. That audible heart-rate alarm was the best training tool I could have had for staying within my AT.'

**It Gives Stimulus to Change:** A monitor brings awareness of limits and can suggest how to change. One person found that just going up a flight of stairs pushed her heart rate beyond her threshold. Her solution was to stop halfway and rest. Another person says that lifting her daughter pushed her over the edge. Her solution was to sit down and have the child climb on to her lap. A third person found that many activities put her over her limit. She has found ways to be active with less exertion. For example, she now uses a rolling chair in the kitchen, empties the dishwasher in stages, and uses a grabber to pick up things without having to bend over. A fourth person echoed the idea by saying that being aware of the importance of controlling her heart rate helped her to slow down: 'My natural tendency is to move quickly and multi-task. Knowing the importance of heart rate motivates me to slow my overall pace.'

**It Educates Others:** A heart-rate monitor helps educate others about limits and to elicit their help. As one person said: 'Using the monitor helped my family to understand and they help me to stop when it goes off.'

### **Summary of Benefits**

To summarise the benefits of awareness of heart rate, here are the thoughts of one person who has used a heart-rate monitor:

I've made a lot of progress in the past year, mostly thanks to heart-rate monitoring, which trained me to reduce my activity to a level my body can handle. By forcing myself to stay within my limits, I have slowly achieved an increase in what I am able to do without going anaerobic.

I can walk up a full flight of stairs *and* walk down the hall *and* brush my hair before I need to sit down for a bit. I've learned to be grateful for these small things. They add up to bigger things. I feel well most of the time now and although I can do very little, it's more than I could do six months ago.

### **Morning Resting Heart Rate**

The strategies above show how you can use observations of your heart rate during the day as a tool for staying within your energy envelope. You can also use what is called the morning resting heart rate in combination with a simple log for the same purpose.

You can determine your resting heart rate by lying down shortly after get-

ting up in the morning but before taking any stimulants such as coffee, noting your heart rate at that time. By doing this for a week or two and keeping a simple log of your symptoms and energy level, you can determine your baseline morning heart rate, and also should see patterns between overactivity one day and subsequent elevated heart rate. The elevation often occurs on the next day, but may appear two or three days later. Here's how one person describes her use of this technique:

I used the average of my heart rate over two weeks to determine that my baseline resting heart rate is 66 beats per minute. By keeping daily records, I found that if the heart rate at that point in the day is five or more beats higher than that threshold, I continue to have a higher than usual heart rate and increased fatigue for the rest of that day or even longer. I also noticed that the increased pulse rate can often be predicted by the level of activities and stress in my life in the day or days previous to the raised pulse.

When I have an elevated morning heart rate, I replan my day to have less activity than normal and more rest. I can avoid increased symptoms if I double my normal daily flat-rest time and postpone all high-intensity activities until my morning resting heart rate stabilises again at 66 or below.

### **Should You Monitor Your Heart Rate?**

Many people with a wide range of severity in their ME/CFS and/or FM have told me that they value monitoring, so I suggest that they all explore to see whether monitoring heart rate might be beneficial for them. Those who have benefited the most from monitoring their heart rate tend to be people with ME symptoms that range from moderate to severe, from those who are active for a maximum of two or three hours a day to those who are bed-bound, and people with POTS (Postural Orthostatic Tachycardia Syndrome).

These people often exceed their threshold doing everyday activities. By monitoring their heart rate and adjusting how they go about their activities, many find they can slowly improve and increase the activity that they can handle without triggering a rise in symptoms.

Other people with ME/CFS may also benefit. For example, finding my anaerobic threshold enabled me to determine the level of exercise that I could tolerate without triggering post-exertional malaise. Staying within my AT helped me regain strength and further reduce my symptoms.

If you are interested in finding your AT, you can start by making note of your heart rate while resting and also check to see whether your heart rate increases dramatically when you carry out activities such as standing up, climbing stairs or just being active for a few minutes. If so, you may benefit from monitoring your heart rate and learning to keep it below your anaerobic threshold.

\* \* \*

Formulas for calculating range of AT for a person aged 50:

a) Maximum Heart Rate = 220 minus Age.

$$(220 \text{ minus } 50) \times 50\% = 85.$$

$$(220 \text{ minus } 50) \times 60\% = 102.$$

b) Maximum Heart Rate = 206 minus 88% of Age.

$$[206 \text{ minus } (50 \times 0.88)] \times 50\% = 81.$$

$$[206 \text{ minus } (50 \times 0.88)] \times 60\% = 97.$$

## Mindfully Evie: On Improving

This time last year, I started seeing physical improvements in my health for the first time in seven years.

It wasn't much at first: just being able to open my bedroom blinds a quarter of the way to let some light in.

And then leaving my bed and going downstairs for an hour every few days.

And then the improvements got a little bigger.

Staying downstairs for longer and more regularly.

FaceTiming family and friends, seeing their faces for the first time in four years.

No longer needing to wear sunglasses 24/7 or plugging my ears when the Hoover went off.

Being able to wash my own hair again.

Then, writing for one hour turned into a whole morning, and then morning and lunch.

Even though I feel my recovery has stalled a bit in 2021, mainly due to my injury, winter and lockdown more than anything else, I have come *such* a long way in a year.

So today I am celebrating one year of remission.

One year of beginning to reverse the other seven.

One year of travelling along the path of visible physical healing.

One year of starting a journey of self-discovery outside of these four walls and my illness label.

One thing I will say is this past year has *not* been the year of 'finally living' or 'getting my life back'.

I still had a life when I was at my worst.

I still had meaning when I was bedbound.

I was still living when my world was confined to one room.

My life was just as meaningful and valuable a year ago as it is today.

Don't let yourself believe or let others make you believe that you're only 'living' when you're improving.

Or that you only have meaning when you can do things.

Because I promise you, no matter how big or small your world is, how much or little you can do:

You are still living a life that is meaningful and valid.

You *are* still living.

This celebration today is not a year of getting my life back.

It's celebrating a year of finally seeing the physical healing I worked towards for seven years.

It's celebrating that all that trust I put into believing I was healing even when I couldn't see that the visible progress paid off.

It's celebrating beginning a new path, new journey, and a continuation of self-discovery and healing.

Happy one year of visible physical healing to me.

Mindfully Evie's website is at <https://mindfullyevie.com/>.

## 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.

██████████ has continued with her painting, and has produced quite a few new ones, including these delightful sun and moon motifs. You can contact her at ██████████.



## Library Suggestions

If there are any ME-related video, audio, pamphlet or book resources that you think the Group Library should hold, please e-mail your suggestions to [REDACTED] at [REDACTED].

## The Disability Law Service

The Disability Law Service (DLS) provides free advice via information fact-sheets, training courses, and telephone and written advice. Within its current funding it is able to provide telephone advice in areas of welfare benefits, housing, community care and employment and discrimination law. The DLS does not provide tribunal representation in court (although this could be possible for housing benefit).

The DLS is based at the Human Rights and Social Justice Centre at the Foundry, 17 Oval Way, London SE11 5RR (near the Oval). The benefit advisor at the DLS is Richard Conway. To contact him, call 020 7791 9800, and then use option 5; leave a message and he will call you back. On-line advice can be obtained via its website: <https://dls.org.uk/free-advice/online-advice/>.

## Benefit Queries

If you have questions in respect of your benefits that need answering, please send them by e-mail to [REDACTED] at [REDACTED] or [REDACTED] at [REDACTED], and they will be forwarded to Ken Butler, the expert on benefits at Disability Rights UK, who will attempt to answer them.

## 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.

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## Listening Line

The Group's Listening Line is a support service to help members with the emotional burden that comes with living with ME. [REDACTED], who is in charge of it, is a friendly person with previous experiences of helping people through counselling. She 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 this is not a helpline dealing 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 [REDACTED] will call you when she is available. Please be aware that she will not be able to answer your call after 6.00pm as she needs to rest.

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## Helplines

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. There is an e-mail contact at [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk).

<b>Richmond and Kingston ME Group Committee</b>		
Chair	Vacant	
Secretary	Vacant	
Treasurer	██████████	████████████████████
Membership Secretary	██████████	██████████████████████████████
Project Coordinator	██████████	██████████████████████████████
Members' Support	Vacant	
Committee Member and Group Library	██████████	██████████████████████████████
Committee Member	██████████	██████████████████████████████
Social Secretary	██████████	██████████████████████████████
Newsletter / Website	██████████	██████████████████████████████

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

Facebook	██████████	██████████████████████████████
Listening Line	██████████	██████████████████████████████
Interview Tape Recorder	██████████	██████████████████████████████
Twitter	██████████	██████████████████████████████

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

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

**Twitter** — @randkmegroup (see our tweets on home page of the Group website)

**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.

	<p>The Richmond and Kingston ME Group is grateful for the generous financial assistance that has been provided by Waitrose.</p>
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