

Richmond & Kingston

ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

NEWSLETTER

No 4, 2021

Inside — Sutton ME Services — [REDACTED]'s Ten Questions — What Our Members Are Doing — And More...

A NICE Result!

It was with considerable pleasure — and not a little relief — that on 29 October 2021 the National Institute for Health and Care Excellence (NICE) finally issued its revised clinical guidelines for the treatment of ME. The new NICE guidelines represent a definite advance for the treatment of our illness compared with the deeply problematic NICE guidelines that were issued in 2007.

What the New Guidelines Say

Aimed primarily at health and social care professionals, the new guidelines give a clear and accurate description of ME, stating that it is 'a complex, chronic medical condition' for which 'there is currently no cure'. ME 'affects everyone differently' and its impact 'varies widely'; it is a 'fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer'. It can affect 'different aspects of the lives' of those with the illness, 'including activities of daily living, family life, social life, emotional wellbeing, work and education'.

Helplines Information: See Page 15

The guidelines outline the various levels of ME, showing four categories from Mild, through Moderate and Severe to Very Severe, and giving a potted description of how each category impacts upon people. They then give in detail the symptoms which define ME:

Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.

Post-exertional malaise after activity in which the worsening of symptoms is often delayed in onset by hours or days; is disproportionate to the activity; has a prolonged recovery time that may last hours, days, weeks or longer.

Unrefreshing sleep or sleep disturbance (or both), which may include feeling exhausted, feeling flu-like and stiff on waking; broken or shallow sleep, altered sleep pattern or hypersomnia.

Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

In what might be interpreted as a veiled criticism of the baleful impact of the superseded guidelines and of the psychosocial 'it's all in your head' school of analysis which influenced previous official thinking about ME, the guidelines note that people with ME 'may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness', that they 'may have lost trust in health and social care services and be hesitant about involving them', and recommend that health and social care professionals must take this into consideration in order that 'supportive, trusting and empathetic relationships' can be established.

The guidelines confirm the clauses in the draft versions that health and social care professionals must take into consideration that 'there is currently no cure (non-pharmacological or pharmacological) for ME/CFS', and repeat the disavowal of two treatments — Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) — that were recommended in the 2007 NICE guidelines as adequate ways of dealing with ME, and which have been claimed by the psychosocial school as cures for the illness.

Based on criticisms in the qualitative evidence of cognitive behavioural therapy (CBT) being described as a 'treatment' (cure) for ME/CFS, the committee considered it was important to highlight that CBT is not a cure for ME/CFS and should not be offered as such. Instead, it aims to improve wellbeing and quality of life, and may be useful in supporting people who live with ME/CFS to manage their

symptoms and reduce the distress associated with having a chronic illness. It should therefore only be offered in this context, and after people have been fully informed about its principles and aims.

As for physical exercise, the revised guidelines are very clear:

Physical activity has a health benefit for most people and many conditions, but in people with ME/CFS, physical activity may make their symptoms worsen...

The committee concluded any programme using fixed incremental increases in physical activity or exercise (for example, graded exercise therapy), or physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories, should not be offered to people with ME/CFS. The committee also wanted to reinforce that there is no therapy based on physical activity or exercise that is effective as a cure for ME/CFS.

Following from this, the guidelines call upon health and social care professionals to help people with ME to 'develop a plan for energy management as part of their care and support plan', and to 'support them to establish realistic expectations and develop goals that are meaningful to them'.

The revised guidelines take a look at the Lightning Process, stating sternly that for various reasons it 'should not be offered to people with ME/CFS'.

There is also a section relating to the specific problems facing children and young people who have ME.

NICE's Peculiar 'Pause'

The road to the ratification of the revised guidelines was by no means straightforward. Those responsible for the ideas that influenced the previous NICE guidelines for ME, the psychosocial school, waged a furious and devious fight against the new proposals. They recognised all too well that what was being offered stood in stark contrast to their prescriptions for dealing with the illness — that is, GET and CBT — prescriptions that people with ME recognised were, as in the case of CBT, merely of limited use in dealing with the *symptoms* of ME, or, as in the case of GET, actually harmful to many people.

NICE had by last August prepared the final draft of its guidelines, but, rather than meeting to ratify it, it suddenly declared a 'pause' in the ratification process, and instead proposed to hold a round table discussion on 18 October. This dismayed many people with ME and the ME campaigning groups. It was quite unprecedented and of dubious legitimacy, and not surprisingly made us fear the worst, making many feel that the psychosocial school and certain obdurate Royal Colleges had managed overly to influence or even to nobble the NICE committee.

Looking back, however, perhaps something closer to the opposite

occurred. Could it be the case that the NICE committee was determined to push through the new guidelines, and called the pause in order to put the psychosocial school and the Royal Colleges in a confident frame of mind, giving them a false sense of security, to fool them into thinking that they had the committee in their pocket? Seeing that the final version of the new guidelines aims a massive blow at the psychosocial school and puts paid to both their jealously-held position as the main authority in Britain in respect of the treatment of ME and their recommendation of GET and CBT as all-purpose cures for ME, this is a distinct possibility.

Putting the Changes into Practice

The medical world can be strangely slow to adopt practices that subsequently come to be recognised as beneficial and indeed essential. When Joseph Lister first recommended disinfecting wounds and surgical instruments, he was mocked by many top medical professionals and authorities. Consider the length of time during which the psychosocial school was considered by the medical establishment as *the* authority on ME in Britain, despite the repeated exposure of the inadequacies of its theories and the ineffectiveness of its practice.

And so, the point made by Neil Riley, the Chairman of the ME Association, that ‘it’s one thing to have a guideline, quite another for medical professionals to adopt new treatments and help us to recover’, is extremely pertinent. In recognising that the new guidelines represent a significant shift in clinical practice, Physios for ME enquired as to who will be providing training to support teams to adapt their practice, and how these changes will be overseen and monitored.

ME Action has initiated the Dear Doctor campaign, which is aimed at encouraging GPs and other health professionals to read the new guidelines and to recognise the fundamental changes that they present:

We need your help to tell doctors and other medical staff that the recommended treatments for people with ME have changed. We want to get the message out that there are new recommendations on the way people with ME can be supported, but they should not offer harmful treatments like Graded Exercise Therapy.

ME Action has also presented a five-point recommendation which it feels will acquaint health professionals with the key innovations in the guidelines:

- ★ Understand and recognise that people with ME may have experienced prejudice and disbelief and could feel stigmatised by people... who do not understand their illness
- ★ Do not offer any programme that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy.
- ★ Provide care flexibly to the person’s needs, such as by on-line or phone consultations or making home visits.

- ★ Be aware of how to diagnose ME and be confident in recognising it. It is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer.
- ★ Signpost people to support groups, give advice on financial and social support, and access to aids and adaptations.

The revised NICE guidelines represent a very welcome change in the treatment of ME; they show that they have been compiled by people who not only are familiar with the specificities of ME, but also have taken into account the research into ME that has been undertaken in other countries and what people with ME have long been saying about their illness and how it affects them. It is essential that their recommendations are implemented immediately and thoroughly throughout the health and social care sectors.

The Richmond and Kingston ME Group is grateful to the NICE panel reviewing the guidelines, to the ME Association for its contributions, to health professionals, ME support groups and people with ME for their input, and especially to Caroline Kingdon and Dr Luiz Nacul from the UK ME/CFS Biobank Cure ME Project at the London School of Hygiene and Tropical Medicine, who used the testimonies provided by our members to help the campaign to remove GET and CBT as treatments for ME.

Paul Flewers

Book Review

██████████ reviews Sarah Ramey, *The Lady's Handbook For Her Mysterious Illness* (Doubleday Books, 2020).

* * *

The Lady's Handbook For Her Mysterious Illness is, at heart, a call for a new approach in dealing with WOMIs (women with a mysterious illness) from both those of us suffering from a mysterious illness (including MOMIs) and those who aim to support and treat them. This approach is based on functional medicine, and Sarah attributes much of her own improvement to this.

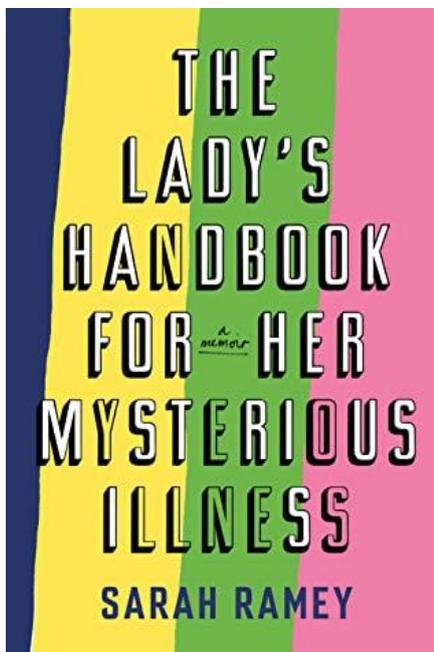
Her book is written largely as a memoir in which she describes her experience over 10 years with an illness that defied diagnosis despite intense (and horribly intrusive) testing and which doctors then decided must therefore be all in the mind:

One urologist who had just performed this really horrible procedure took me into his office with my parents. Instead of talking to me, he looks at my parents and says, 'You know, this test was negative. What

I really think is going on here, like so many other young women her age, is this problem is psychological.'

Originating in a 'seemingly innocuous' illness in college, it became a long-term and elusive condition that destroyed her health, but one that doctors could neither diagnose nor treat. Eventually she got a diagnosis of Chronic Fatigue Syndrome (she is American), which she describes as the diagnosis you get when doctors have nowhere else to put you.

It is a familiar story starting with a visit to a doctor and expectations of a cure, followed by tests that mostly come back negative (I was described by my doctor once as 'abnormally normal'), and when out-of-range results appear they are dismissed (mine were always described as 'atypical'), periodic breath-



taking incompetence (often arising from poor preparation/inability to listen by the doctor, the sense of isolation and failure (is it just me?), the discovery of a community (she calls this WOMI), the search for 'alternative solutions' (think yoga, kale smoothies and positive thinking), and the moments of optimism and subsequent despair as the illness fluctuates.

It is also a book that challenges the male-dominated perspective of medicine. In the worst of times, Sarah starts to reflect on the fact that the overwhelming majority of people with chronic invisible diseases are women, and also to note, for example, that because of the inconvenience of a monthly cycle in women that may affect results, new drugs are almost invariably tested only on men

— even though there are major differences in how men's and women's bodies work in ways that could be highly relevant. The book's tone changes markedly here as she stops passively accepting what doctors (traditional or alternative) say. She starts to consider these differences and what this might mean for medicine.

And it is from this insight that she starts to focus on a more holistic ('feminine') approach to health that will not be about cutting it out or a silver bullet pharmaceutical. For Sarah, there is redemption — if not a complete cure — from functional medicine, and this is a key insight that she wants to share.

Functional medicine sees today's chronic illnesses as ecological in nature, driven by modern changes to the basic foundations of health, from the quality of our sleep, diet and social connections to the state of our microbiomes. So a basic premise of functional medicine is that these chronic illnesses are the result of an individual's history which it is vital to understand, and which is so different from our general experience of doctors. So while there may be common building-blocks to recovery, each individual's path will be different.

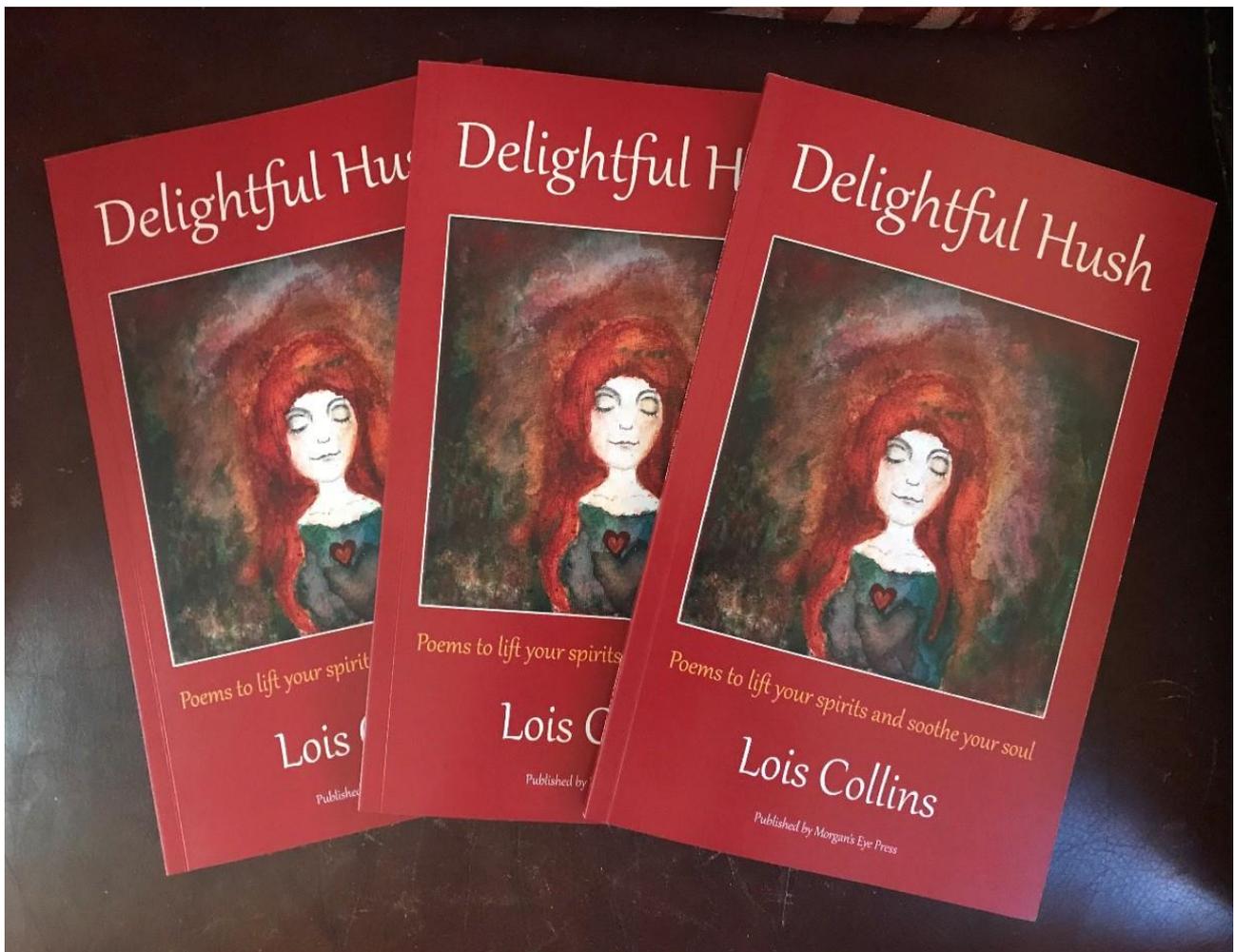
The kicker at the end is that it turns out that she also has something that traditional medicine should have picked up and cured, resulting from a botched surgery for her initial problem. But this can be seen as the trigger event that sent her spiralling down an all too familiar path.

Sarah Ramey has written a very readable, darkly funny, memoir; she has learnt a great deal about how the body works; she has tried more interventions that most of us; and finally she has found sustainable improvement from a gentler and more balanced individualised approach.

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.

We're delighted to announce that [REDACTED]'s book of poetry and paintings has been published by Morgan's Eye Press. If you'd like to order one, please contact her at [REDACTED].



Paul Flowers had an article on the theory of state collectivism published in the *Weekly Worker* for 2 December. He still has some copies of the book he recently edited on the final years of the Weimar Republic in Germany, *1933: Warnings From History*, on sale for £10 (bookshop price: £15.99). If you'd like a copy, e-mail him at trusscott.foundation@blueyonder.co.uk.

Ten Questions

This time answered by [REDACTED].

- 1) **How long have you had ME?** I was first diagnosed by my GP in 2017 but at the time no one explained to me what this diagnosis meant, and it wasn't until March 2020 that I realised the severity of the diagnosis as my body finally collapsed from the stress I was putting it under.
- 2) **What was the trigger that started it off?** It is not very clear what my trigger was, but we believe it was a mix of typhoid infections, PTSD and stressful life events.
- 3) **What is the worst thing about having ME?** I feel like this answer changes each week. Even as I write this I keep deleting and changing the answer. I think the worst things for me are the aspects of my life I have lost. I had to leave South Sinai which was the place I had chosen to make my home, I have lost my independence, lost my meaning and purpose which I found through my work in marine conservation, lost many friendships. I don't think I realised how much ME was a journey of grief. I think that's why it changes each week because each week there is something new to grieve.
- 4) **Has anything good come of it?** Alongside the grief has come immense self-reflection and a great deal of learning. I have learnt so much about who I really am which has allowed me to find a wonderful partner, peace within myself and in life.
- 5) **What treatment (prescribed or alternative) has helped the most?** I have started to work with a naturopath in the last three months and I feel there has been a significant change in my energy, brain fog and pain. We have worked on my sleep and diet as these were two big problem areas for me. I now eat an anti-inflammatory diet, which feels amazing. I also take a few supplements which the naturopath tailored to me to help me sleep, heal my gut, and boost my immune system. During the last few years, I have also seen a psychotherapist of the Human Givens teachings as I had specific things I knew were affecting my nervous system in the wake of my PTSD and a stressful career. Working on these specific things with the psychotherapist have really calmed my nervous system and reduced my anxiety. Lastly, I have found meditation to be a great help, again to calm my nervous system.

- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Luckily, I have not yet used a treatment which has not helped me in some way. I have been lucky to receive a lot of advice from the ME community before embarking on anything which I think has significantly reduced wasted treatment.
- 7) **What do you like doing on a good day?** On a good day I *love* anything involving nature even if it's sitting somewhere comfortable with a good view of the sea or trees. If I'm at home then I enjoy cooking with my family, calling a friend, or being creative through art.
- 8) **Do you have any tips for getting through a bad day?** Find a good TV series or podcast and escape to another world through it. That's what I usually do. Something I have also had to learn is to not be hard on myself. I would say that learning not to be negative about what I can or can't do on the bad days has helped me a lot.
- 9) **What is the worst thing anyone has said to you?** When a doctor couldn't find a reason for my bad health, they told me: 'It's just women's problems.' That made my blood boil because I hate being dismissed for my health, but I hate being dismissed for being a woman even more!
- 10) **And the best?** My friends and family being so proud of me. When they tell me they are proud, that gives me so much strength.

Extra questions:

- 11) **Where would you like to be now?** I would like to be on top of a mountain in Scotland overlooking the sea with maybe a few whales and dolphins passing by! Not sure if that is the answer you were looking for but that's where my mind went straight away.
- 12) **Tell us a joke/mantra/quote.** My friend sent me a video of Michaela Cole's Emmy acceptance speech: 'Do not be afraid to disappear. From it, from us, for a while. And see what comes to you in the silence.'

A Meeting with Sutton CFS Service

We held an hour-long Zoom meeting with the CFS Service at Sutton Hospital on 13 October. Dr [REDACTED], Consultant Clinical Psychologist and Team Lead, and [REDACTED], Clinical Nurse Specialist, were there on behalf of the Clinic, whilst our member [REDACTED] plus committee members [REDACTED], [REDACTED], and [REDACTED] were there on behalf of the Richmond and Kingston ME Group. [REDACTED] chaired the meeting and took the minutes.

It started with a warm greeting from [REDACTED] to the attendees and an introduction for [REDACTED], a new Clinical Nurse Specialist, who was welcomed by the group.

The first topic on the agenda was the impact on patients' perceptions

caused by the Service having a psychiatrist as the lead consultant. [REDACTED] highlighted that we probably had a perception of Dr [REDACTED] that might not reflect what she actually does at the Service. [REDACTED] asked for evidence or feedback from any of our members experiencing an increase of psychological influences on the treatments and services provided by the Clinic, as Dr [REDACTED] has not influenced any of them. Although she is a psychiatrist in her other job, she is at the CFS Service to ensure its operation and the receiving of funds from the NHS Trust as the Lead Consultant, but she is *not* there to change the treatment by implementing more psychological therapies or to treat the illness as a psychological rather than physiological condition. Dr [REDACTED] is employed as a medical consultant in the CFS Service so that she can provide a medical opinion on patients' referrals to exclude conditions other than ME/CFS, ensuring that they are at the right place for their treatment.

[REDACTED] explained that Dr [REDACTED] had set up the Service in 2004, finding the funds and resources to run it. He has retired and no other immunologist showed interest in running it. There aren't medical consultants trained to be ME/CFS Specialists, and no one in the country applied for the post.

As ME/CFS doesn't have a known proven cause, there is not a 'home' for the illness within NHS Trusts in the country, so each local NHS Service has to find and justify the resources it needs, based on demand, in order to treat the condition, and Dr [REDACTED] ensures funds are assigned to the Sutton Clinic for this purpose.

The next topic on the agenda was the suitable use of CBT to help patients to manage anxiety and negative thoughts as a consequence of having ME/CFS. [REDACTED] mentioned that CBT helped to deal with unhelpful thoughts, feelings and behavioural responses, along with adjusting to living with ME/CFS. Whilst some people may see the logic of identifying alternative thoughts, they do not necessarily feel reassured and they continue to experience challenging emotions. The Service has been able to adopt Third Wave CBT approaches such as Compassion Focussed Therapy (CFT) and Acceptance and Commitment Therapy (ACT). Therapy includes developing skills related to acceptance and applying self-compassion in the context of aligning a person's life in accordance to their values.

In order to adapt their programme to the new NICE Guidelines, [REDACTED] proposed an open meeting with all ME/CFS support groups in the South-West London and Surrey areas to talk about this process. The Service considers and values our feedback (which influenced them sufficiently to be one of the few CFS services that did not recommend their patients to use Graded Exercise Therapy). This meeting might be arranged within the first half of 2022.

[REDACTED] asked about the areas covered by the Service, and [REDACTED] said that they were all of Surrey, part of North-East Sussex and the part of South London adjacent to Surrey.

[REDACTED] said that the Service used the Hospital Friends and Family Test

for feedback, based on whether users would recommend it to other people with ME/CFS, and on comments about how to improve it or what could be performed better. In the last 12 months, 126 people have provided feedback and 92 per cent said they would fully recommend it. Just two per cent of respondents declared that they would not recommend it, and they are being approached in order to find out their reasons so that improvements can be made.

Regarding Long Covid, the Sutton CFS Service is working collaboratively with the Long Covid Service at Leatherhead Hospital. Both services are exchanging information, but are not planning to merge. They have access to the new research on Long Covid and the recommendations for treating the condition. ██████ highlighted that the Long Covid Service must be cautious when recommending GET to their patients as this could worsen their symptoms, especially Post-Exertional Malaise (PEM). Patients with Long Covid, as well as with ME/CFS, need more rest in order to recover. She also asked why patients with Long Covid received support from many different medical specialities, due to many physiological systems being affected, whilst patients with ME/CFS are left with minimum resources.

██████ mentioned that ME/CFS symptoms were exacerbated by the perimenopause and it would be good to see more information about it given by the Service.

██████ said that the Service was seeing around 200 patients per year when it was originally set up, but in recent years that number has increased to 600, within the same budget. As the local Long Covid Service had been established, the CFS Service has avoided the risk of an increase in referral demand. There were currently no plans to expand the part-time working hours.

Regarding the possibility of suspending the current automatic discharge of patients once they complete the First Steps programme, ██████ said that it was not feasible, as the Service would have to re-absorb all these patients, thus leaving new patients with longer waiting times. ██████ explained her case and ██████ was sorry to know her situation, but demand currently exceeded the resources they had available.

██████ said that the Service provided a discharge letter to GPs explaining what the patient learnt at the sessions and how to manage setbacks. ██████ suggested that it would be helpful to include a sheet with resources for patients about benefit applications, support groups and ME websites such as the ME Association. ██████ also mentioned that they should provide a support letter for us to apply for PIP and other benefits when applicable. ██████ said that they write supporting letters for patients that are active in the Service. They are unable to write supporting letters for those no longer at the Clinic, as this would require time and resources they currently don't have. She and ██████ also said that some of the resources are flagged at the beginning of the process, when patients first join the Service, but ██████ pointed out that patients didn't tend to remember what was told on the first appointment as they were all trying to

understand and adapt to the changes in their bodies and to a new way of living their lives with the limitations and strong symptoms caused by the illness.

About the possibility of recommending the use of Heart Rate Monitoring for patients (so they can pace themselves better), ██████ mentioned that it was used by the physio in specific situations for some patients, as heart rates changed with stress, eating food, digestion, etc. ██████ commented that there was an application that could be used for patients in order to prevent PEM. She said that understanding how to operate it was 'a bit techie', but ██████ said that they could signpost patients to it, requesting help from the physio when needed. ██████ had wanted to recommend Physios for ME, but there was insufficient time to do so.

The good news for severe patients (and everyone!) was that the Service had finally received the authorisation from the NHS Trust to use on-line appointments. This turned out to be only way that people could become patients during the Corona pandemic and therefore appointments have become solely on-line over the last 18 months. The Service was now trying to work using a hybrid system where patients could be seen in person and on-line.

Fernando thanked ██████ and ██████ for talking to us and ██████, ██████, ██████ and ██████ for attending and for asking good questions and offering suggestions. ██████ thanked the Richmond and Kingston ME Group for being supportive to the Service by being in touch and offering constructive feedback. The next meeting, to be held in 2022, will be used to discuss the implementation of the new NICE Guidelines.

If you would like to see the full minutes, please contact any member of the committee.

Mindfully Evie: I Just Want To Be Seen

It's not you.

It's me.

It's years of being misbelieved.

Years of being dismissed.

Years of being told it's just stress.

Years of being turned away from help because I didn't look ill enough.

I know your intentions are good.

I know you think you're saying a nice thing.

But I constantly feel like I have to prove that I'm sick.

That I'm not a faker.

A liar.

An imposter.

Living with an invisible illness does that to you.
It asks you to prove how you're sick.
But if you could see the pain, the fatigue, you would never ask me to prove it
as you will see it in its fullness.
But on the street, in a picture, in passing, you can't see this.
You can't see how sick I am.
That is why it hurts when you tell me how well look well.
It hurts because it feels like you're saying I'm not sick.
That my illness isn't real.
Or that I'm not as sick as I'm claiming I am.
Too much history and messiness of being accused of being a liar, a faker, an
imposter, is brought up through your words.
I know your intentions are good.
But please understand, as someone with an invisible illness, it hurts when
you tell me I look well.
I don't want to feel like I have to prove anything.
I just want to be seen.

Letter from ME Research

We received the following letter from [REDACTED], the Operations Director at ME Research.

On behalf of all of us at ME Research UK, I would like to thank Richmond and Kingston ME Group so much for its continued support and its donation of £75 received this morning. I have, as on previous occasions, credited the donation to our Research Fund — 100 per cent of which is dedicated to funding biomedical research into the causes and consequences of ME/CFS.

The past 12 months have been difficult for us all, but, paradoxically, it has been an extraordinarily active period for ME Research UK. Our 2021 call for grant applications focussed on the viral causes of ME/CFS closed last month and received six high-quality proposals from around the world. We are also currently looking at three applications for PhD funding. Two newly funded projects are starting this month, while we have another 10 studies on-going, altogether representing more than £1 million currently invested in ME/CFS research. The next few months will also see previous years' research projects ending and we look forward to sharing the results and adding still further to the knowledge-base of this illness.

Without the support and faith of our friends none of this would be possible.

Once again, I would like to thank Richmond and Kingston ME Group so much for the donation; every penny helps us in our quest to make the breakthrough that ME/CFS sufferers deserve.

It is gratifying to see that our donation is being used to help finance important research into our illness.

Listening Line

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

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

WhatsApp Group for All Ages

We currently have a WhatsApp group for young adults with ME. However, we have received e-mails from members of different ages who would like to interact via this smartphone application. If you would like to be included in this group, please contact [REDACTED], our Membership Secretary, at [REDACTED].

Contingency Fund

Please remember that you can apply for help from the Group Contingency Fund not only to pay for taxis or other travel expenses to see your GP/Consultant, but also to pay for their medical report and your medical information in the NHS system in order to support your benefits application. We have received lots of feedback about the difficulties of applying for PIP and other benefits; therefore, we consider that it is essential that you obtain an

updated report from your GP, which usually costs between £25 and £50. Remember that this fund can also be used for such things as attending Group meet-ups and benefit assessments, or in a family emergency.

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

Benefit Queries and Helplines

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

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

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

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

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

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

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

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

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

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

Twitter — @randkmegroup (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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