

# Richmond & Kingston

## ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

# NEWSLETTER

**No 3, 2021**

**Inside** — ■■■■■'s Story — ■■■■■'s Ten Questions — What Our Members Are Doing — And More...

## **A NICE Outcome?**

The saga of the revised National Institute for Health and Care Excellence (NICE) clinical guidelines for the treatment of ME seems at last to be heading towards a conclusion. A round table meeting was held on 18 October bringing together the Royal Colleges, NHS England, ME campaigning bodies and patient organisations, and following from that NICE announced that its Guidance Executive will be meeting during the week starting 24 October, after which they will publish the finalised new guidelines.

We reported in our final newsletter for last year how NICE had been working since 2018 on long-awaited and much-needed new clinical guidelines for ME/CFS to replace the existing guidelines which were considered by ME campaigning organisations and people with ME to be extremely problematic, and we looked at the new draft guidelines that were issued in November 2020.

These draft guidelines stated that there was 'no current treatment or cure (non-pharmacological or pharmacological) for ME/CFS', and disavowed two treatments — Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) — that were recommended in the previous NICE guidelines as adequate ways of dealing with ME.

The draft was hailed by ME campaigning organisations as a great step

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forward. Commentators emphasised that it aimed a blow at the psychosocial school, whose adherents believe that ME is essentially a psychological condition — hence our dubbing them the ‘all in your head’ brigade — and threatened to put into jeopardy both their jealously-held position as the main authority in Britain in respect of the treatment of ME and their concomitant recommendation of GET and CBT as all-purpose cures for ME.

NICE had prepared the final draft of its guidelines in August. These revised guidelines were mainly a refinement of the original text. As with the initial draft guidelines, they gave the distinct impression that they had been researched and written by people who not only have some knowledge of ME, but had taken the bother to listen to what people with ME have been saying about their illness and how it affects them.

The revised draft emphasised that ME ‘is a complex, chronic medical condition affecting multiple body systems’ and that ‘its pathophysiology is still being investigated’. It also noted that it ‘affects everyone differently and its impact varies widely’, and it ‘is a fluctuating condition in which a person’s symptoms can change unpredictably in nature and severity’. The chief tell-tale symptoms of ME were outlined as debilitating fatigue that is worsened by activity, post-exertional malaise, unrefreshing sleep and cognitive difficulties (brain fog). It added that health professionals should ‘be aware that ME/CFS symptoms can be managed but there is currently no cure (non-pharmaceutical or pharmacological) for ME/CFS’.

When it comes to treatment, the revised draft stated that ‘the committee considered it was important to highlight that CBT is not a cure for ME/CFS and should not be offered as such’, although it ‘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’ and ‘should therefore only be offered in this context’.

As for physical exercise, the revised draft was quite categorical:

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 intolerance 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.

The revised draft was completed and signed off by NICE’s guidance executive, and was distributed to NICE representatives and qualifying stakeholders on 4 August. NICE was due to publish its new guidelines on 18 August 2021,

but with less than 24 hours to go, it decided to refrain from publishing them, declared a 'pause' in the proceedings, and instead proposed to hold a round table discussion on 18 October. NICE's explanatory statement raised more questions than it answered, not least when it stated that the 'publication of the guideline was paused when issues were raised by some professional groups during the pre-publication period'. The barrister Valerie Eliot Smith considered that NICE had broken its own procedural guidelines, stating that, 'according to NICE's own manual, when publication took place on 4 August, the process had been completed'. She wrote that 'no further changes could be made from this point onwards, save for minor corrections', and that NICE 'gave no credible explanation or detail of any exceptional circumstances justifying its extraordinary action'.

Many people with ME had the feeling that these 'professional groups' were our old foes of the psychosocial school; after all, the ME campaigning organisations were calling for the revised guidelines to be ratified, released and put into practice. The 'all in your head' brigade were an obvious suspect, and many people wondered if they had nobbled NICE. There are sufficient changes in the draft to whip them into a frenzy, as its recommendations reject what they have long been recommending and upon which treatment for ME in Britain has long been based. They had already shown their disapproval of the original draft guidelines, especially in respect of their sharp criticism of GET and CBT.

So at the time of writing, we are waiting for NICE to release the new guidelines, and then their recommendations, as NICE's Chief Executive Professor Gillian Leng, wrote, 'can be effectively implemented across the system'. Dr Charles Shepherd of the ME Association felt that her statement was 'very welcome', and added that 'the ME patient community can now look forward to publication and implementation of the new NICE guideline on ME/CFS and all the recommendations it contains'.

The draft guidelines offer a vastly improved vista for people with ME, as they reject the practice of GET, which is quite unsuitable and indeed dangerous for our condition, recommend CBT only as a coping mechanism, and also call for genuine medical research into the illness. And so we are hopefully nearing the day when — at last — people with ME will be able to obtain on the NHS treatment for their illness that will enable them better to cope with their day-to-day situation and will not put them in danger of experiencing further health problems as a result of their undergoing unsuitable practices.

**Paul Flewers**

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## **Trampers: Off-Road Mobility**

Although mobility scooters greatly help our freedom of movement, they do have their limitations. Their use is largely restricted to roads and solid paths, and even then they can have problems when surfaces are rough or uneven.

Trampers are all-terrain mobility scooters that are able to overcome these limitations. They will take you where you want to go — and, as they are electric, with no emissions! There are four- and three-wheeled versions, capable of taking their riders over hill and dale, or just to the shops. They give their riders their independence again, and enable them once more to accompany their friends and family on trips to the countryside.

If you would like to try one, there are over 100 available for hire on sites all around the country, including some of the National Trust's premises, where you could hire one. You can join the charity Countryside Mobility South-West (<https://countryside-mobility.org>) by completing a one-page membership form. It costs £2.50 for a two-weeks taster, or £10 for a whole year. As the name suggests, it operates only in the South-West of England.

██████████ had the opportunity to take his daughter to the Eden Project in Cornwall in July. At first, he thought he wouldn't be able to do much in that big complex as his walking was very limited. However, he decided to have a taster with a Trampler and signed up with Countryside Mobility for a couple of weeks. He went nearly everywhere in the Project with his daughter walking alongside (he couldn't put the Trampler on the treetop walk, alas, as it was too high and narrow!) and found the scooter comfy and powerful.

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## **Don't Be Afraid to Rest**

I used to see rest as a punishment or chore — a symbol of my failing by overdoing it. The more I needed to rest, the more frustrated and disappointed I became with myself. This past year I've learnt just how necessary rest is. It's a chance for my body to work less on surviving and more on healing.

The hardest part of rest for me was unlearning the belief that I had to earn it, sometimes I still catch myself doing this. Part of me wishes I could go back in time and tell myself to prioritise rest; that it isn't something that has to be earned or deserved. Rest is productive and necessary for your body and mind — for healing.

Looking back now, I can see that a lot of my health deterioration is due to that lack of simple knowledge, that resting doesn't equate to laziness, that resting is doing. Most people don't view a day or week of rest as an achievement but, trust me, it is. It's not easy not being able to do most things and it's really not easy having to sacrifice and choose rest over the hustle of doing what you still can whilst you can.

So to those reading this who feel like they have to earn rest, trust me, you don't. Rest is necessary, productive and livelihood saving. Rest allows us to have a quality of life, to keep living in whatever way we can and there's nothing insignificant or lazy about that.

There's as much, if not more strength in stopping as there is in pushing

through. Energy management isn't easy and it isn't something that just happens. It takes time and courage to stop. To stop hustling for dreams, for your future. To stop meeting deadlines and ableist goals. Stopping is a skill of strength, courage and determination.

Stopping means believing in maintaining your health and your symptoms more than materialistic goals society expects of you. Stopping is observing life at your own speed whilst learning your limits. Stopping or slowing down doesn't mean giving up, and it certainly doesn't make you lazy or weak. It's a skill most people will never have to learn but with chronic illness it's so important for finding a baseline or maintaining symptoms.

So keep adapting to your symptoms and your life, not to what others expect of you. Resting is productive, energy management is a skill, but stopping is a strength. Please remember on days where hustling is all you can see and think about, that there is as much, if not more strength in stopping as there is in pushing through.

**Daisy Dunne**

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## ██████████'s Story

██████████ has written a diary covering the experience that her daughter ██████████, aged 17½, has had with ME. If you would like to contact ██████████ for more information, please ask any member of the Group Committee for her details.

The Committee does not endorse the therapies and supplements mentioned in this article. We understand that everybody is different and medications, supplements and treatments work in different ways for each person. Try and see what works for you.

\* \* \*

**Easter 2017:** It all started with glandular fever aged 13 at Easter time 2017. My daughter ██████████ never fully recovered and was always complaining of unusual levels of tiredness for the two years after this.

**February 2019:** We went to Wales for half-term and walked up Cadair Idris, a stunning mountain with a crystal-clear lake at the top, and ██████████ cried all the way down from the pain in her legs and the exhaustion. This was the first time I knew something was really wrong. After that it was a slow decline.

**June 2019:** We noticed ██████████ was worse after eating and exercising. She spent the rest of the year deteriorating, bit by bit. More and more time off school, more pain in muscles and joints. Always tired, headaches, constipation, muscle spasms, brain fog. ME was diagnosed towards the end of this year. She was initially put on Naproxen for the joint pain and Omazoprole and Baclofen by our GP. These just masked the condition and didn't fix it. We

were referred to the CFS Service at the NHS University College London Hospitals, but it was 'closed' and we waited until June 2020 to get a telephone appointment. There was no way I was just going to sit back and watch a young girl go through this. There had to be another way.

**22 February 2020:** We finally got an appointment with [REDACTED], a Kinesiologist who came highly recommended by a friend who had multiple health issues, on 22 February 2020. Immediately [REDACTED] was put on a candida diet, which meant no gluten, no dairy, no sugar (including fruit), no yeast or fermented foods, no soy, but rich in protein and vegetables. With a plethora of supplements including Similase, Fungalite, Liposomal Zinc, Magnesium Citrate and Liposomal D3. For the first two weeks she was fine.

**12 March 2020:** [REDACTED] became more ill than she had ever been, practically bed-bound. This lasted two and a half weeks, and then she had three days of slight improvement and went to school. Then she got bad again. She started to have strange symptoms, like feeling she had been pinched really hard in her cheek or leg. The left side of the body would get nerve pain running from the neck all down to her leg. Her headaches never stopped. The whole body was frozen (she said it felt like she had turned to stone) and muscle spasms continued. She was more tired and weaker than ever before. She couldn't control her temperature, either freezing or boiling, nothing in between. Muscle and joints were painful; I could hear them crunch as she walked upstairs. She couldn't bear too much light or noise. We were seeing [REDACTED] again in two weeks and it couldn't come quickly enough. She prescribed Magnesium, Thiamine, Zinc and Glutagenics. [REDACTED] thought [REDACTED] was experiencing a 'health crisis'. On researching what that was, it sounded exactly right.

**May 2020:** Around then [REDACTED] came out of this dark period and started to get better. She started dropping each symptom one by one.

**June 2020:** [REDACTED] had been symptom-free for six weeks. We had a telephone appointment with the CFS Service — finally! — with a lovely doctor called [REDACTED], but unfortunately, the service were unhelpful, as their insistence on pacing activities didn't work for my daughter.

**23 June 2020:** We saw [REDACTED] again and started treating [REDACTED]'s thyroid. She prescribed Vitamin AEK, P5P, Thiamine, Magnesium, Iron Phosphate, and [REDACTED] carried on with the previous supplements. [REDACTED] had a bad period and felt very unwell all week.

**July 2020:** By the time we got to the summer holidays at end of July, [REDACTED] seemed fully recovered, able to do normal things without pain or headaches and sleeping better. We went to France and she swam and even played badminton! She went back to eating sugar and fruit, but still couldn't have gluten or dairy as this caused her stomach aches and constipation.

**September 2020:** Half-way through the month, [REDACTED] regressed. She had white spots on her tonsil, and our regular doctor prescribed penicillin.

This really messed her up. We saw [REDACTED] and she said her gut was bad again, so she told us to start once more with the strict diet as before plus Silver, Zinc and Vitamin C. Additionally, N-Acetyl Cysteine, Bifidum, L Salivarius, B Subtilis, Fungalite Phase 3 and Mitochondrial Support.

**9 October 2020:** [REDACTED] started to pick up a bit and went back to college after a week off. Much improved, but sore muscles still present as well as brain fog.

**10 November 2020:** [REDACTED] was not doing well at all. Her hair had started falling out at the beginning of October and we realised that it was due to lack of vitamin B12, as she had also decided to become a vegetarian back in August; therefore we went back to eating meat to see if this could help. She got lots of headaches, muscle pain and tightness, mainly in the thighs, and her entire body weakened all of a sudden. She couldn't think straight and couldn't speak with ease. She got severe gut pain and her knee joints were sore and swollen. The only upside was that her insomnia hadn't returned. She got a new bed (brought by my Mum) and was far comfier at night.

**21 November 2020:** [REDACTED] was complaining of stabbing pains on her left side below the spleen. It happened every hour and lasted two minutes, and she woke up during the night with the same pain.

**12 December 2020:** [REDACTED] saw [REDACTED], and her thyroid, small intestine and lungs were tested. She was also tested for allergies and medications, but showed nothing there. [REDACTED] worked on her emotions with some tapping. Now she was taking Vitamin D: if she were deficient, could this explain the spasms? Overall, not good at all. Symptoms were joint pain in knees, back aches and stomach pain. She had an issue with her chest feeling heavy and stuffed inside. Exhausted and had headaches in the front of her head. Temperature changed, mainly felt very cold *all* the time. College had finished for now, thank God. One good thing was that her spasms had improved since taking Vitamin D.

**18 January 2021:** [REDACTED] had been very ill for a whole week. Barely got off the sofa. Severe temperature issues, extremely cold *all* the time, no matter how many blankets and hot water bottles. Her feet were frozen. Major migraines, sore joints, lower back pain and stomach pain. Weakness on the left side. Complained of numb leg, exhausted and looked like a zombie. Black bags under her eyes and very pale. Saw [REDACTED] the previous Saturday and was tested for heavy metals in the liver. More emotional work.

**29 January 2021:** We met [REDACTED], the Acupuncturist, for the first time (I had been at my wits' end and had read some amazing results for others with ME). She did some laser work and moxa (a herb you burn) with a couple of needles. She was so gentle. [REDACTED] felt bad straight after, seemed irritated and 'heavy' and exhausted. Spent the afternoon on the sofa, but by five o'clock felt a little better.

We started to see [REDACTED] every week (for five weeks) and she gave [REDACTED]

her acupuncturist diagnosis — spleen deficiency, damp phlegm and liver stagnation (the remedy was movement). We needed to strengthen the spleen and stomach. Put on same sort of diet as previously with emphasis on warming foods like soup. No cold food like salad, and no gluten and no dairy. Giving moxa at home each day made ██████ felt heavy and lethargic afterwards. Constantly tired no matter whether she had slept or not. It could be the start of another ‘health crisis’.

**24 February 2021:** I realised that it was what it was, the health crisis continued. I had started to give ██████ the Anthony Williams Medical Medium celery juice detox a week and a half before (by the way, I had been reading his books avidly for a good year and I was finally implementing his suggestions). He was the only source I had read that told that ME/CFS (and a multitude of other unexplained illnesses) *could* be cured by following his guidance. I became more convinced of this as the weeks progressed.

In the meantime, ██████ was still exhausted with headaches and spots and rashes that came and went away. She hadn’t been to college at all, either physically or on-line. The CFS Service prescribed pain relief to take at night to help her sleep. We never implemented this. More drugs were not good in my opinion, as they were merely masking symptoms and were bad for the gut. ██████ was really good, but it was hard to tell if there was an effect yet. Hopefully something in few weeks.

**1 March 2021:** We saw ██████ for the fifth appointment. ██████ had shown improvement over the last week. Less strong headaches, less pain, and constipation had ended after two weeks of the first month on Medical Medium three-month diet. No eggs, no gluten, no dairy, no soy, and celery juice first thing in the mornings. With celery working wonders on the gut, and alongside ██████ we were getting somewhere at last! My theory was that she was starting to detoxify. She had her whole body itching though (this turned out to be from the first dose of the Covid jab). I thought that supporting the body to fight for itself with the right foods was the key. Celery juice on an empty stomach first thing and then wait at least 20 minutes to eat. This stopped her constipation.

**6 March 2021:** ██████ had a bad day, and was very tired indeed. We saw ██████, and ██████ was tested for colon and small intestine. She found chemicals which probably the Covid jab gave her. I bought Q10 and probiotics to help her for her second jab. Also tested on that day for Epstein-Barr Virus (EBV), which she found deep in the tissues and therefore more emotional work was needed. She talked about despair and holding on to trauma.

**11 March 2021:** ██████ still felt bad. Saw ██████ again and she worked on her head and legs and did moxa too. On the following day I noticed that ██████ seemed to be better each time after seeing ██████. We decided to pull her out of college. Pointless to carry on as she would not pass by now. Too much stress anyway! She felt relieved!

**1 April 2021:** We were near the end of the second month of detox and



though [REDACTED] couldn't continue on celery after six weeks of it (it had started to make her feel sick), she carried on with lemon water and some ginger instead. The diet continued, no eggs or pork (feeds EBV), plus new supplements and acupuncture. There seemed to have been a shift. She also got a closure over the nasty bullying back in Year 7 and 8 through her friend. The stress of college had gone too and it all helped. She used to be on an 8/10 for pain every day, now it was 4/10. Sleep improved greatly plus I had been talking to the angels and I thought they were helping!

**13 April 2021:** [REDACTED] was still improving. Had one bad day last week, but overall had been very good. Slept ten hours a night and didn't complain of pain at all. The main things remaining were morning headaches, some upper back pain and fatigue, although fatigue didn't have her on the sofa all day anymore. We were going to the Lake District in four days and was hoping that she could cope with the walks.

**27 April 2021:** By now we had done two huge uphill walks and though it was a struggle, [REDACTED] managed them. One bad day whilst away and the day after we went back home. She had seen [REDACTED] one day ago and had a good session with her. She had to pop to the doctors for blood pressure check and she rode her bike there and back! She was tired but happy! No more daily headaches, no muscle or joint pain. She slept well, looked better and was able to be up and functioning every day. There was still some fatigue and occasional soreness but her skin had improved too. [REDACTED] worked next on her emotional side, trying to help her anxiety. She sunbathed and her skin looked better. I was cautiously optimistic. We had two more weeks of the three-month detox, but were inclined to continue as it was working amazingly well.

**11 May 2021:** [REDACTED] was doing so well. She had finished the three-month detox, but we were carrying on with it. We were seeing [REDACTED] every two to three weeks and she had given [REDACTED] Bach's flowers remedy, made specifically to help her anxiety. After a week of taking them, she said that she had fewer negative thoughts and worries. It had been a full month with no pain, no headaches, no insomnia, no constipation, no joint pain or cracking, no spasms and even her skin had improved. She had the second Covid jab and felt really unwell for 36 hours. The only thing left was some tiredness, which was a 3/10 instead of a 10 three months ago. I thought then that we might have just cracked this thing. Huge thank you to the angels too!

**1 June 2021:** [REDACTED] said that she wanted to earn some money and keep herself busy. I used the street WhatsApp to ask if anyone had any babysitting, gardening or anything for her and they came up trumps! She now had a job two days a week doing social media for a PR/marketing company owned by [REDACTED] at the end of the road. She looked after [REDACTED]'s guinea pigs and [REDACTED]'s garden. She had energy and was feeling really good. We were still carrying on with the Medical Medium diet generally, but very occasionally she would have a normal piece of bread or some regular cheese and there was

no ill effect. Had seen [REDACTED] last week who had worked on [REDACTED]'s itchy eyes, which I actually thought was just hay fever. She was motivated and energised and therefore we now know what fixes her. As we relaxed the diet and saw less of [REDACTED] and [REDACTED]; if anything happened, we knew what to do.

**1 September 2021:** We had just come back from holidays and had a wonderful time. [REDACTED] felt great, so much that she tried eating both gluten and dairy and had no reaction. She swam every day, went on walks, had no symptoms at all! She has enrolled in college to study Animal Management at Capel Manor College and is excited to be starting a new phase of life, free from pain, insomnia and lack of energy. She still works for [REDACTED] and has more babysitting and gardening jobs lined up. She is saving her money and wants to buy a laptop. Last but not least we are going skiing for her eighteenth birthday next year!

In conclusion, it seems that with a lot of perseverance and research, we have reached our full wellness goal! I have to say thank you to the wonderful [REDACTED] and [REDACTED]. Without their care and support we would have never got here.

And to anyone who is suffering with this hideous illness (and others), there is hope! Hippocrates said 'All disease begins in the gut', and I have to say I now fully believe that you can heal completely through it too, with the right foods and right support, you can be well again.

Good Luck and all the best.

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## Ten Questions

This time answered by [REDACTED].

- 1) **How long have you had ME?** I have been ill since 1996, so about 25 years, but it had been creeping up on me for very many years. I thought it was old age!
- 2) **What was the trigger that started it off?** The pandemic of around 1958. I was told I had had pneumonia and pleurisy, but the late Dr [REDACTED] told me it was more likely to have been a virus and what used to be known as Bornholms syndrome, also known as pleurisy.
- 3) **What is the worst thing about having ME?** Thinking I can do something and then not being able to finish, or only get a bit through it.
- 4) **Has anything good come of it?** No.
- 5) **What treatment (prescribed or alternative) has helped the most?** Accepting what is... is.
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Exercises at Charing Cross Hospital. I only went once and virtually collapsed when I arrived. The doctor refused to agree that just getting there was all I could do.

- 7) **What do you like doing on a good day?** Pottering around. Busy doing nothing sort of day. Audio books. A film.
- 8) **Do you have any tips for getting through a bad day?** For me it is important that I eat four meals a day. A piece of fruit, a slice of toast, a Kit Kat; anything but never miss a meal. I lose weight easily.
- 9) **What is the worst thing anyone has said to you?** 'You're drunk', when I have a balance problem. I don't drink as it gives me migraines.
- 10) **And the best?** 'I'm trying to understand.'

Extra questions

- 11) **Where would you like to be now?** In a Winnebago trundling around the United States to see where some of my ancestors lived when the USA was a colony.
- 12) **Tell us a joke/mantra/quote.**

A man in a very red coat  
 Tripped up and fell into a moat.  
 He said I'm feeling better  
 When I'm feeling wetter  
 And spent the rest of his life in a boat.

Made up by me over 50 years ago.

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## The Me I Used To Be...

The me I used to be.  
 Energetic, sporty  
 and full of beans.  
 Now anxious waiting  
 for a seat upon which to lean.


The me I used to be.  
 Proud to work and  
 earn my keep.  
 Now rolling down a cliff edge  
 regardless of how deep.

The me I used to be.  
 Spontaneous, eager for  
 the adventure trips to begin.  
 Now inactive, flabby  
 the opposite of what  
 we might call thin.

The me I used to be.  
Reliable and never needing  
my plans to fold.  
For after all I'm strong  
it's only a little cold.  
Now confined to bed  
rolling around in unimaginable pain.  
The equivalent to a horse  
flailing on its back due to being lame.

The me I used to be.  
Confident, assertive and  
sometimes up for a fight.  
Encouraging the guys to  
look me in the eye, wondering  
at my unspoken delight.  
Now lost and feeling like  
an empty shell.  
Vulnerable and missing  
those vital cells  
to function and perform  
these vital tasks.  
Now struggling to shower  
what a goddam farce.

Through all of this mayhem  
it does take its toll  
But I wish I knew who I've become,  
just please god not this lost soul



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## **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.

## 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 completed a book of poetry and paintings, and copies should be available soon. ██████ has produced quite a few more of her delightful paintings. You can contact her at ██████████.



Paul Flowers has had a couple of letters published, one on the radical tradition within the Anglo-Catholic wing of the Church of England, in the *London Review of Books*, 9 September, and another on the green economy and capital accumulation in the *Weekly Worker*, 2 September. Paul also has some copies of the book he edited, *1933: Warnings From History*, on sale for £10, a

fair bit cheaper than in the shops. If you'd like a copy of these eye-witness accounts of the final years of the Weimar Republic in Germany, e-mail him at [trusscott.foundation@blueyonder.co.uk](mailto:trusscott.foundation@blueyonder.co.uk).

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## **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.

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## **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/>.

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## **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].

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## **Listening Line**

The Group Committee is happy to announce that we have a new volunteer, [REDACTED], to assist with the Listening Line. This 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 peo-

ple 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.

## 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].

## 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.

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.

## Many Thanks!

The Group Committee extends its thanks to [REDACTED] and [REDACTED] for all their hard work in managing the Group's Twitter account and the Listening Line respectively. [REDACTED] has taken over the Listening Line, and [REDACTED] is managing the Twitter account until we find a new volunteer.

| <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                                | ██████████ | ██████████████████████████████ |
| 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.

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|  | <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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