

Richmond & Kingston

ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

NEWSLETTER

No 3, 2022

Inside — What Our Members Are Doing — *Pulling Through* Reviewed —
██████████' Ten Questions — And More...

Putting the Fun into ME Fundraising

R+KME Group Committee member ██████████'s niece ██████████ and her friends ██████████ and ██████████ did several challenges over the summer holidays to raise money for the World Wildlife Fund and ME biomedical research (the London School of Health and Tropical Medicine's UK ME Biobank). You can see just how much they enjoyed hosting a homemade cake stall and a stall selling preloved items.

Afterwards they sent the following message to their neighbours:

Well thank you so, so much to everyone who came and supported the girls' sale — and apologies to those who arrived after the cakes had sold out! — their total currently stands at £192.01. We will keep you posted once the girls return to school as they are planning to do a mini sale for their classmates as well which should boost their total.

Helplines Information: See Page 15

The second challenge was a sponsored cartwheel extravaganza, for which they each pledged to perform 1000 cartwheels. Incredibly it was completed by all three girls in one afternoon!



Next was an overnight challenge where they stayed out in [REDACTED]'s garden overnight, cooking their dinner and breakfast on a tiny stove, sleeping in hammocks.

Finally, there was a tree-climbing challenge for which they climbed up a tree and stayed up there to eat lunch and to while away a number of hours, each balanced in her own spot. They rigged up a series of pulley systems so they could send each other notes and a bucket to lift their food into the tree!

The R+K ME Group wished [REDACTED], [REDACTED] and [REDACTED] lots of luck and plenty of fun when they told us about their challenges, and we now wish to thank them very much for raising money on behalf of two such worthy causes.

Ten Questions

This time answered by [REDACTED].

- 1) **How long have you had ME?** Two and a half years.
- 2) **What was the trigger that started it off?** Covid19.
- 3) **What is the worst thing about having ME?** Not being able to do things I used to enjoy. Being gaslit by medical professionals. Friends/family not understanding.
- 4) **Has anything good come of it?** Yes, I have learned to put myself first, to take each day as it comes and to not sweat the small stuff.
- 5) **What treatment (prescribed or alternative) has helped the most?** I have found acupuncture really helpful in managing the fatigue; I also have fibromyalgia-type symptoms so acupuncture helps with pain management. I have also been tapping meridian points as per Donna Eden's book *Energy Medicine* and Wim Hof's cold therapy method. I would recommend both books as I have found elements from both quite helpful so others might find them useful too!

- 6) **And which was the most useless or did the most harm (to you or your pocket)?** I haven't had anything that hasn't help at all; even the things that haven't helped physically such as massage or seeing an osteopath have made me feel more relaxed and in a better mindset.
- 7) **What do you like doing on a good day?** I enjoy reading, light gardening chores or meeting up with a friend for a cup of tea.
- 8) **Do you have any tips for getting through a bad day?** Focus on the small wins instead of the things you can't do and be kind to yourself.
- 9) **What is the worst thing anyone has said to you?** 'Oh we all get tired', 'You're young, you'll get over it.'
- 10) **And the best?** I'm proud of you for trying to remain positive and focus on the things you can do, rather than the things you can't.

Extra questions:

- 11) **Where would you like to be now?** On a Mediterranean beach with a mojito in my hand!
- 12) **Tell us a joke/mantra/quote:** 'Normality is a paved road. It's comfortable to walk, but no flowers grow on it.' — Vincent Van Gogh.

Book Review

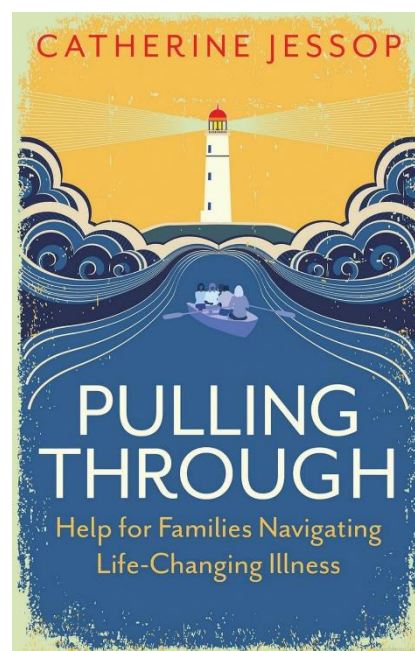
██████████ reviews Catherine Jessop, *Pulling Through: Help for Families Navigating Life-Changing Illnesses* (Jessica Kingsley Publishers, 2021).

* * *

This is not a book about ME or caring for someone specifically with ME. But it is an extraordinary account by Catherine Jessop of her experience from the moment one Boxing Day when her husband was suddenly struck down with encephalitis, and what she has learned about dealing with having a family member with a life-changing illness.

The book is structured more or less as an account of her life over the years after her husband first collapsed with seizures, through diagnosis, 11 months in hospital and his return home (treated but not cured and still requiring periodic emergency treatment). This sets up suitable points to discuss what she learnt relevant to the different stages of their experience.

For anyone navigating their way through sudden and scary hospitalisation of a family member, this gives advice on how to



deal with hospitals and doctors, and more generally to get help and support — practical, financial and emotional. Some of the tips, helpful explanations and the glossary are very straightforward and some will be familiar, while others demonstrate a lot of reflection on her experience and that of those around her. What struck me was the breadth and detail of her insights; for example, who can help in different situations from the state to charities, what to ask for from friends, what to tell young children, how to stay cheerful, how to look after the patient *and* the carer...

Catherine did not experience any disbelief that anything was physically wrong, but encephalitis is another mystery illness, and it affected her husband in ways people around her didn't understand. Her absence of self-pity is so complete that you find yourself brought up short by throwaway lines that demonstrates just how ill her husband is.

I found this book personally interesting for its insight into aspects of the probable experience of those around me when I contracted shingles and never got better, developing instead an ever-increasing set of bizarre symptoms. But the book is more usefully a practical guide for carers who find themselves suddenly facing caring for someone in their family who experience a life-changing illness.

What Our Members Are Doing

Done anything exciting, inspiring, interesting? Although ME does its best to make our lives miserable, 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 a delightful medallion which she's holding here. Lois can be contacted at ██████████, if you're interested in her paintings, medallions, stones and mugs.

██████████ has just completed this wonderful embroidery of Pablo Picasso's famous painting *Guernica*, his response to the bombing of the town of Guernica in April 1937 by German and Italian aeroplanes on behalf of Franco's forces during the Spanish Civil War. ██████████ says:

I was 'drawn' to this work. Painted



mostly in black and white, it is a stark image that is very dynamic compositionally. I was keen to explore this through embroidery — a new-found skill, much less taxing than painting or drawing, a necessary adaptation to chronic fatigue.

But there was another reason for my interest, a hidden one, which I hadn't recognised until later. Those fractured figures and their obvious distress, as their town was bombed.

Their loss of wholeness through painful change, both mentally and physically, resonated with me most as I struggled then and now to come to terms with an untreatable and life-changing condition.



██████████ has also been busy with embroidery. Her street scene is making steady progress, and promises to be an excellent work. Here's what she says about it:

While in hospital years ago I did an embroidery of a peacock on a black background which turned out so well that I had it framed and my parents had it on the wall in their sitting room. It wasn't an easy embroidery but not too difficult either. I decided I wanted something a bit more difficult for my next embroidery. So I looked for something complicated.

I found this street scene and it was marked as level four (most difficult); I really liked the street scene so I bought it. To say it is difficult is a bit of an understatement. I have now been embroidering it for over 25 years. Quite often it takes roughly half an hour to do about five stitches. It depends which bit of the picture I am working on. I am currently working on the balloons and it is very laborious. You can see

one of the pink balloons top left of the picture. I am doing yellow ones just now, which are above the pink one, and the thread is very hard to distinguish from the backing cloth, so finding the right place to bring the needle up for each stitch is a big strain on the eyes.

I am very pleased with what I have done, but I wonder if I will ever finish it.



██████████ has been engaged in what she calls 'doodle art'. She tells us:

Although my health has been improving slowly and I'm married to a supportive husband and we have a beautiful 12-year-old daughter, like many moderate to severe ME sufferers, I spend most of my time at the moment housebound and alone, in our two-bedroom, third-floor flat. As well as the many debilitating symptoms that ME brought, starting in the mid-1990s, I've also been struggling with profound boredom, intense anxiety and depression over many years. I've always enjoyed making art and being creative (our shared human condition), so it occurred to me to find easy, simple, fun creative activities, that I could do to improve my quality of life.

That's when the idea came to me, to start making 'doodle art'. I then asked my daughter to pick any seven colours she liked and started working on the piece shown below, several months ago. I'm allowing the piece to develop organically and I'm really enjoying the process, mainly because I'm not taking my art too seriously and I'm not putting pressure on myself with a specific outcome or completion date. This is truly about having a fun!



I've also been taking photos, doing some writing, doing a few, gentle dance and other movements, as well as doing other easy, creative activities that take my fancy! Being part of the Richmond and Kingston ME Support Group has also made a real difference my quality of life, as I've been able to join various activities, as little or as often

as I can, all from the comfort of my living room or bedroom. So big thank you to the organisers and members of this group.

██████████ is a regular attendee at the Group's on-line Crafting Meetings. She finds crafting stimulating and below are a couple of her recent productions. She tells us:

My current project is using essential oils as a stimulus, and cutting and sticking-painting and writing poems in response to the senses and words the oils stimulate. For this piece I was using Rose oil on my burner as the stimulus. At the last Group Crafting session I cut out more pictures from magazines to use for my next one. This is a low-energy and easy task, and I also find it mindful. I am not sure yet if I will choose Violet or Yarrow oil next...



██████████ will be telling us in the next newsletter how she finds doing jigsaws helps with her ME symptoms.

The Group's on-line Crafting Meetings give the opportunity for members to display and discuss their creations. If you've not attended one of them and would like to, visit our website to find the date of the next meeting.

Our Thanks to ██████████

The R+KME Group Committee thanks ██████████ for all her hard work in the post of Membership Secretary. She was a vibrant part of the team and we wish her all the best for the future.

Meetings with Richmond and Kingston Healthwatch

The Richmond and Kingston ME Group and Healthwatch have been in touch for many years, exchanging information via sporadic gatherings and consultations.

██████████ had a meeting with Healthwatch Richmond (HWR) at the end of November 2021, and a couple of meetings with Healthwatch Kingston (HWK) in April and June 2022. These meetings have been helpful as they have enabled us to collect information about services available in these boroughs. Some of them are replicated in boroughs and counties across the country, hence if you live in a different place, please read this article as you could find something helpful in your local area.

It was very useful to know that colleagues from at, or their relatives, have ME and/or Fibromyalgia. As they can understand the condition quite well, they have created a section on their website dedicated to us, where people can find different services available in this borough. Please have a look at the following link: <https://www.healthwatchkingston.org.uk/advice-and-information/2022-05-26/all-about-myalgic-encephalopathy-me-and-fibromyalgia-services>.

HWK have prepared a survey to be completed by people with ME and/or Fibromyalgia living in the borough (or outside) in order to gather more information about our needs. With this information on hand, they will be able to approach the NHS Clinical Commissioning Group (CCG) and the Council to request more provision for us. The survey is not long and we will be able to share our experiences with an organisation that understands us and which will try to seek the services and help for which we're looking. Please see this link: <https://www.healthwatchkingston.org.uk/share-your-views>.

Meanwhile, HWR have provided a good source of information about different services in the borough. They have also taken notes of the difficulties we face, in order to notify the CCG covering the area.

For instance, for us, seeing a GP and attending appointments on time is difficult, in addition to the physical and mental effort of attending an appointment at the surgery. HWR said that on-line appointments with GPs have been possible at Seymour House in Richmond: <https://seymourhouseandlockroad.co.uk/>.

However, phone and Zoom appointments can also be difficult and tiring, because we get sensory overloaded. They took note that the main issue for us was our being excluded and put on waiting lists if we couldn't manage to attend. We need hospitals and dentists to have a deeper understanding of our difficulties in getting to appointments. Home visits would be helpful. Dentist would be

helpful if they were more flexible. HWR said they would feed back to local institutions the need for continuing flexibility of appointments, incorporating the choice to have remote appointments, when possible, even after the pandemic, and the use of home visiting or on-line appointments. They would also feed back that the consequences when a patient with ME misses an appointment are inappropriately severe. The NICE Guidelines say that the illness is neurological and therefore real, so medical practitioners should not disbelieve patients.

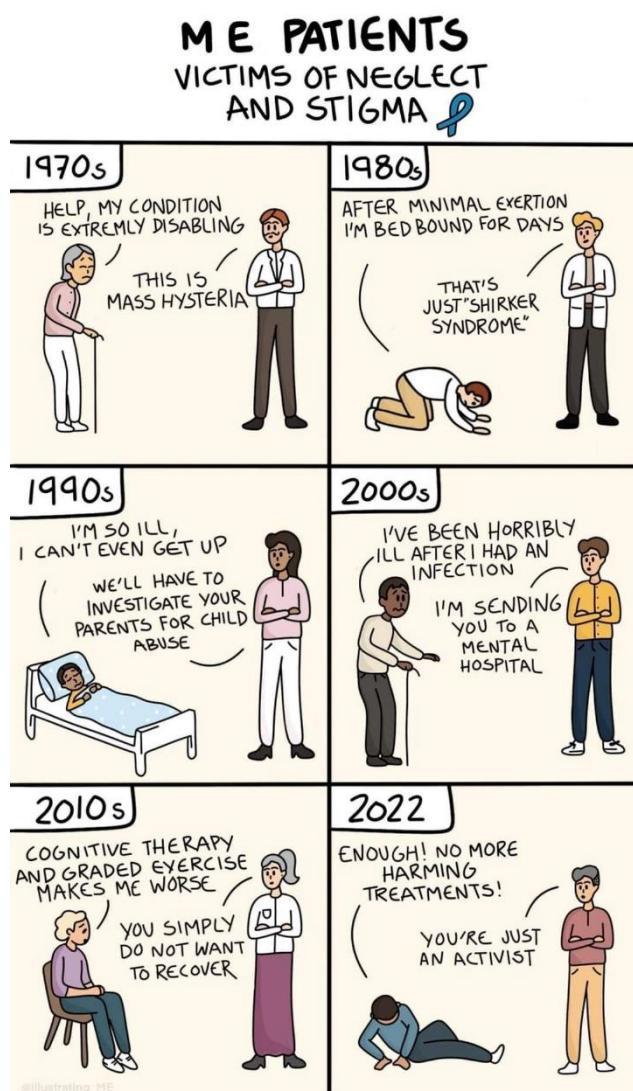
Some branches of care have specific services that allow for home visits or flexibility, such as community dentistry: <https://www.kch.nhs.uk/service/a-z/community-special-care-dentistry>.

██████ mentioned that the CFS Clinic at Sutton Hospital was providing on-line appointments for patients with ME. HWR will feedback this to the CCG, so that they could at least incorporate this modality when home visits aren't possible.

Doctors who do not believe that ME is a real medical condition and therefore do not schedule home care have been a serious issue for us. People who

live alone would find helpful the support from social care for tasks of daily living, but many of us struggle to be referred to these services and to reach the minimum threshold for them. HWR called Social Services and confirmed that they accept self-referrals and assess patients on the basis of needs rather than on the basis of diagnosis, which was reassuring to hear. You can find out more about the assessment process and eligibility, and contact details, at https://www.richmond.gov.uk/media/17480/asc_who_qualifies_for_care_and_support.pdf. It should be noted that most boroughs and counties are also offering this service.

Applying for a blue badge has been difficult due to the nature of the illness. Even with a letter from GP, members can get rejected by the authorities because of a lack of recognition of their condition. HWR said that the local advocacy service qualified to help with this was ReThink at wandradvacency@rethink.org or on 0300



7900 559. Apparently, their system is quite busy and takes time to respond. HWR would like feedback if this is the case for any of us applying for this service.

Information and support from the R&K ME Group has helped members to understand their own condition and get support. Medical professionals are not aware of ME support groups or do not provide information about them. Fernando has e-mailed the Group's ME Awareness booklet to HWR so it can be distributed at GP surgeries in the borough.

The local authority Direct Payments Scheme which enable disabled people to pay for carers is not recognised for people living with ME. The core problem is the lack of recognition by GPs that ME is a condition which qualifies for this scheme. [REDACTED] has e-mailed the new NICE Guidelines to HWR for them to be forwarded to the CCG so that the illness can be recognised as a neurological condition. However, as mentioned before, we can now self-refer ourselves for an assessment call with the council, or we can contact RUILS (www.ruils.co.uk) to ask for financial support, as they organise the scheme in Richmond.

The R&K ME Group created an information pack for teachers, so they can understand how to treat children with ME, and met with the school nurses for Richmond three years ago. The same applies to GPs, but with some of them not recognising the illness, children and parents feel unsupported. The new NICE Guidelines have some references to children and it would be good if GPs referred to these guidelines when parents seek support. Information will be distributed through the CCG.

ME is an illness that produces severe symptoms in patients and this leads to depression and fatigue affecting their mental health. [REDACTED] said that Surrey provided a service where patients could refer themselves, particularly for long-term illness such as ME. HWR said that similar services were available in Richmond, given by Richmond Wellbeing Service, operated by the NHS, which can be accessed through self-referrals and habitually provides CBT or counselling. The self-referral form can be found at <https://gateway.mayden.co.uk/referral-v2/41a07c00-5142-4ce6-bf95-49374e49fbcf>.

There is also Richmond Borough Mind, which has a variety of support services, including peer support groups and befriending: details at <https://www.rbmind.org/our-services/peer-group-network/>.

Regarding befriending services, some ME patients are having problems being referred on to services by GPs. Whenever this happens, we could use the above link for Richmond Borough Mind. However, members could also talk about social prescribing with their GPs, if theirs is supportive.

As for the perpetually arising question for someone trying to help people with ME — 'Can someone help with a local ME clinic? — HWR will feed back the absence of a ME/CFS clinic in South-West London to the CCG.

HWR has a helpful signposting directory for health services in Richmond

at <https://www.healthwatchrichmond.co.uk/sites/healthwatchrichmond.co.uk/files/Healthwatch%20signposting%20booklet%20-%20final%20proof.pdf>.

██████████ thanked on behalf of the Group HWR and HWK for these meetings, for all the help they can provide with the issues highlighted, for the helpful information given and for the help Healthwatch has provided to the Group over the years.

Advising Health Professionals

You can arrange for your GP Surgery, or any healthcare professionals with whom you're in touch, to receive information from the ME Association, such as the *Purple Book* and the *ME Essential* medical magazine, by submitting their details through this link: <https://meassociation.org.uk/healthcare-professionals-me-cfs-magazine/>.

If you're in touch with your GP by e-mail, you could let him or her know that Doctors with ME provide an excellent executive summary and suggestions on how to give patients with ME the best medical care. It's also very useful for people with ME. It's available via this link: <https://doctorswith.me/nice-gp-update/>.

Greg Crowhurst — For Severe ME Day

We remember them with sadness that they are no longer here with us,
We remember them with frustration that they were not helped,
We remember them with anger that they are gone.
For we remember,
All the hurt,
All the denial,
All the extremity of pain,
All the neglect,
All the harm,
All the harrowing moments,
All the suffering,
All the grief.
And we weep with gratitude,
For their precious lives,
For their tremendous personal strength,
For their utmost conviction,
For their forthrightness in speaking out,
For their passion in life,
For their compassion to others.

In a hostile, empty world,
We remember and give thanks,
For who they were,
And who they will always be,
In our hearts.

Mindfully Evie — It Takes Courage

It takes courage to slow down in a world so encouraging to speed up.
It takes courage to rest in a world where exhaustion is seen as a sign of success.

It takes courage to stop and breathe in a world ploughing ahead at full speed.
It takes courage to stay present in a world so busy looking ahead.

It takes courage to go with the flow in a world telling you to plan.

It takes courage to stray off the main path in a world so closed to alternative routes.

It takes courage to believe you're enough in a world telling you you're not.

It takes courage to go your own way in a world so supportive of mainstream paths.

It takes courage to believe in yourself in a world encouraging you to be someone else.

It takes courage to let this moment be enough in this world telling you to strive for more.

Simple Recipes — Chorizo Stew

Here's an authentic Spanish dish, and very nice it is too. It's enough for two people. If you don't eat meat, you can use a vegetarian chorizo sausage, but as this doesn't contain much oil, you'll need to fry it in some olive oil.

Ingredients

One chorizo sausage, 200g to 250g

One medium onion

Three medium cloves of garlic

Two large peppers or equivalent

Tomato passata, half a 500g pack

Fresh basil, chopped, tablespoon

Fresh parsley, chopped, tablespoon

Vinegar, tablespoon

Black pepper, ground, a little

Rice, sufficient for two people

Cooking

- ★ Chop the sausage into thin slices, and fry gently in a pan until crispy on the outside — it will fry in its own oil — remove and put aside.
 - ★ Chop the onion, garlic and peppers into thin strips, and fry gently in the sausage oil until the onions are translucent.
 - ★ Add the tomato passata, vinegar, herbs and seasoning, and the sausage slices.
 - ★ Stew gently for 30 minutes; add more vinegar if necessary.
 - ★ The sausage is usually quite salty, so no salt is usually required in the stew.
 - ★ Boil the rice with some salt, and allow to drain.
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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.

Benefit Queries and Helplines

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

support your application. [REDACTED] and [REDACTED] can also send any queries on your behalf to Ken Butler, the benefits advisor from Disability Rights UK, who will attempt to answer them.

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 [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/>.

Group On-Line Social Meetings

Our Group on-line social meetings have been very helpful for our bedbound and housebound members, as they enable them to interact with other members from their beds and sofas after months or years of isolation. Some severe ME members have attended with their cameras and microphones turned off and just listen to the conversations, finding in this a very helpful companionship.

If you haven't been able to join us but might like to, please get in touch by contacting [REDACTED] at [REDACTED]. If you need better equipment in order to access our on-line meetings (a new PC, laptop, tablet or smartphone), we can assist you with £50 via our Contingency Fund.



Richmond and Kingston ME Group Committee		
Chair	Vacant	
Secretary	Vacant	
Treasurer		
Membership Secretary		
Project Coordinator		
Committee Member and Group Library		
Committee Member		
Social Secretary		
Twitter		
Newsletter		

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

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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