

Richmond & Kingston

ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

NEWSLETTER

No 1, 2023

Inside — ██████████'s Ten Questions — What Our Members Are Doing —
Annual General Speech — And More...

Group Online Meetings: 250... and Counting!

On 24 February the Richmond and Kingston ME Group held its two hundred and fiftieth online meeting. We have been running online meetings since the start of the Corona Virus Pandemic in April 2020. Like many people, we assumed that the virus would be short-lived and that we would be able rapidly to resume our frequent café meetings. However, this was not to be, and, although we have recently resumed our café meetings on a limited basis, the virus is still unfortunately with us, and we have accordingly continued with our online meetings.

There is usually a silver lining to a dark cloud, and we soon discovered that our online meetings were being attended by group members who for various reasons — distance, disability, convenience — had not attended our café meetings.

We run several types of online meetings. Each month we have two two-

Helplines Information: See Page 15

hour general coffee meetings, starting at noon or two o'clock in the afternoon; one 'pub' meeting at six o'clock; two mindfulness meetings, one crafting meeting and one silent reading meeting at four o'clock. Details of the particular dates of all our meetings can be found on our website.



We are very grateful to [REDACTED] for all her hard work in coordinating the online meetings.

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

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 just what I want.
- 4) **Has anything good come of it?** Better understanding of disability.
- 5) **What treatment (prescribed or alternative) has helped the most?** Pacing.
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Misunderstanding how much I needed to rest initially.
- 7) **What do you like doing on a good day?** Cycling.
- 8) **Do you have any tips for getting through a bad day?** Remember that I've got through it before.
- 9) **What is the worst thing anyone has said to you?** 'I've been feeling quite tired too.'

10) **And the best?** 'You're making great progress.'

Extra questions:

11) **Where would you like to be now?** Skiing.

12) **Tell us a joke/mantra/quote:** You can get through it.

Circle of Disturbance

A useful hint from Greg Crowhurst.

* * *

If you care for someone, especially someone in great pain and who is extremely hypersensitive to noise, touch, light, movement, chemicals, it is helpful to be aware of a circle around you, called the Circle of Disturbance.

What is yours like? Have you just blundered into the room, noisy in your thoughts, uncentred in your actions, distracted in your energy, busy in your being?

As I discover over and over again, it is a sure recipe for disaster and worse, if my Circle of Disturbance is all over the place.

The fact is, when someone is so profoundly ill, your presence is bound to have an impact, but by becoming more aware of your Circle of Disturbance, you can vastly minimise that.

Not only that: when you think about it, if we all minimised our Circles of Disturbance, what an impact that would have on a global scale, especially in terms of caring for the environment.

AGM Speech: The CFS/ME Biobank

The Richmond and Kingston ME Group was delighted to have as guest speaker at its online Annual General Meeting on 15 October 2022 Caroline Kingdon, Specialist Research Nurse at the UK ME/CFS Biobank from the CureME Research team at the London School of Hygiene and Tropical Medicine.

Caroline started the presentation explaining what a biobank was. In summary, it is a large-scale biomedical database and research resource containing biological samples with in-depth genetic and health information from a substantial number of participants. The database is regularly augmented with additional data and is globally accessible to approved researchers undertaking vital studies into the most common and life-threatening diseases. Biobanks are a major contributor to the advancement of modern medicine and treatment, and have enabled several scientific discoveries that improve human health.

She continued with some reasons for having and using biobanks, such as improving cost-effectiveness and time-effectiveness of research, as well as its standardisation and quality assurance. They support the formulation and testing of hypotheses, the understanding of disease pathways, the investigation of disease subgroups, and the discovery of biomarkers.

They use different resources to collect data, such as blood pressure (seated and standing), hand-grip strength, waist circumference, height, weight and bioimpedance, spirometry and pulse oximetry, results of clinical laboratory tests, symptoms assessment questionnaire, participant phenotyping questionnaire, medical outcomes survey, pain and fatigue scales, general health questionnaire, to name just some.

In respect of ME/CFS, samples had been shared widely and anonymously with different scientists in the UK and in other countries, such as the USA, Canada, Germany, Austria and Australia, after following peer reviews of their intended research and ethical approvals. The priority areas for research are hypotheses on pathophysiology of ME/CFS, improving case diagnosis and stratification, discovery of a biomarker, and the basic science potentially leading to clinical trials.

Caroline continued talking about the specific research being carried out by the Cure ME team and its participatory approach, taking into consideration epidemiology, public health, health impact and disability assessment; clinical signs (handgrip strength, blood pressure, etc) and routine and enhanced laboratory tests (for example, cytokines); immunology (for example, T-cell biology); genetic expression (for example, similarities between severe ME/CFS and MS); virology (for example, herpesvirus infection); genomics (for example, potential genome-wide association studies GWAS); health education and health services research.

The CureME team have undertaken four studies, funded by the US government via the National Institutes of Health (NIH) with ongoing support from the ME Association. Their NIH RO1 study, *A Longitudinal Immunological and Virological Study for ME/CFS*, was renewed in 2017 and is coming to the end of the second phase of an eight-year project, which began in 2013 and was interrupted by the pandemic in 2020. Participants were seen by a research nurse up to five times over several years. At each visit they had a clinical assessment, bloods taken, and completed questionnaires about themselves and their health. The study has generated a wealth of clinical data, which is being analysed in conjunction with laboratory results. The high number of recruits (over 600 individuals), multiple time points, and rigorous protocols for the integration of laboratory and clinical information will allow powerful epidemiological and biomedical conclusions to be drawn.

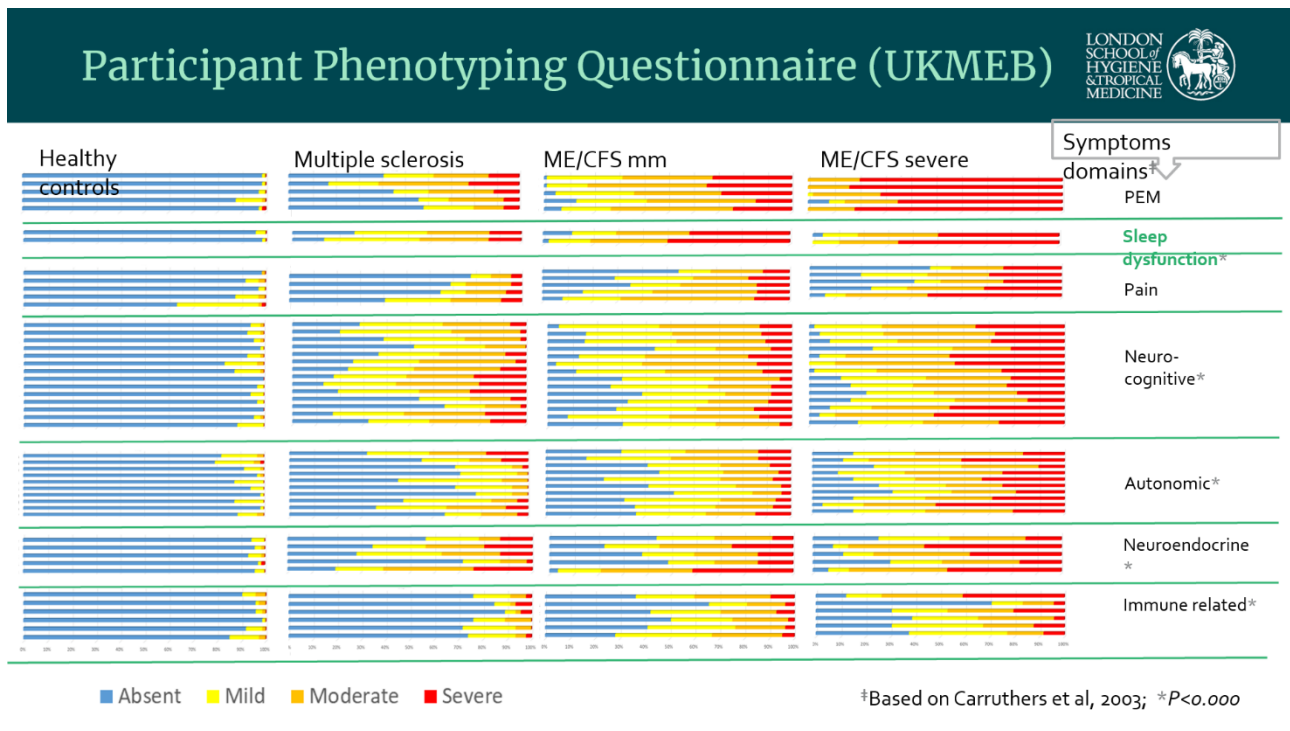
Their second US NIH study involved 60 participants sending saliva and urine samples at regular monthly intervals over six months. The study looked for associations between herpes virus infections and ME/CFS, and piloted a

new assay that aims to detect and quantify viral loads from people with ME/CFS at monthly intervals.

Their third study, funded by the ME Association’s Ramsay Research Fund, was a collaboration with Dr Jo Cambridge and Fane Mensah at University College London. The two institutions looked at T- and B-cell abnormalities in ME/CFS, and conducted extensive immunophenotyping and metabolomic analyses to conduct further explorations into potential biomarkers within these cell subsets.

Their fourth project is a two-year award from the ME Association’s Ramsay Research Fund, to provide support for the Biobank and to accelerate the release of samples to approved researchers from around the world. The award includes funding for ongoing Biobank staffing, maintenance, storage and release costs, plus capital for developing the Biobank’s international profile with the aim of opening new income streams, reducing risk and creating a sustainable business model, independent of research grant support.

Caroline showed the following slide, comparing patients with Multiple Sclerosis (MS), severe ME, moderate ME and healthy individuals.



An important question asked by the CureME team is: how can we best serve people with ME/CFS? Caroline said that patients needed diagnosis, services, treatment, respect and support, and therefore research needs to address better diagnosis and/or biomarkers, pathophysiology, stratification of cases, effective treatment and delivery of services. Fourteen publications have been produced by the team since 2019 covering these topics.

Caroline spoke of what she personally had learned from visiting people with ME/CFS, defining the severity of the illness for patients who were quite

mobile as mildly or moderately affected and the ones housebound or bedbound as severely affected. As many had reached barriers, they were alienated from statutory healthcare services, but were sometimes well connected through social media, and often had more knowledge of ME/CFS than the healthcare practitioner (HCP). She mentioned that it was a challenge for practitioners to visit people with ME/CFS because there is no effective treatment, because it necessitates great wisdom, compassion and skill, and because they may feel vulnerable as the patient often knows more about the disease. Appointments are often time-consuming, quite often cancelled, yet are always a true privilege.

From analysis of the data collected, the team found that 100 per cent of patients with severe ME/CFS had unrefreshing sleep, disabling fatigue and exercise intolerance; 96 per cent had muscle pain, concentration problems and difficulty in finding words; 95 per cent had short-term memory problems and brain fog; 91 per cent had unusual sensitivity to light and/or noise; 89 per cent had difficulties in retaining information; 88 per cent had new sensitivities to food, medication, chemicals, smells and odours, difficulties in understanding, and slow thinking; 84 per cent had pain after exertion/activity; 81 per cent had intolerance to standing/POTS and intolerance to heat and cold; and 80 per cent had allergies/hypersensitivities.

The CureME team believes that compassion is integral to any interaction with patients with ME/CFS. Compassion describes the way in which care is given through relationships based on empathy, respect and dignity. It can also be described as intelligent kindness and is central to how people perceive their care. HCPs should allow enough time for phone calls and visits, use a tone of voice and physical contact appropriate to the individual, allow time for physical tests and for questions and responses.

HCPs must be careful never to cause deterioration of the patient's condition, the agenda should be prioritised according to the patient's need, avoid any sensory overload such as noise, smell or light; take care not to introduce infection: handwashing, remove shoes, cancel if unwell; be sensitive to the individuals as their visits are often long-awaited. Patients may spill over with things to say or find it difficult to speak at all.

HCPs must show competence, that they must have the ability to understand an individual's health and social needs. It is also about having the expertise, clinical and technical knowledge to deliver effective care and treatments based on research and evidence. The HCP should listen to the patient, who may have extensive knowledge of ME/CFS; some ideas may be erroneous and need gentle correction, but practitioners should always acknowledge where they stand with their professional knowledge of ME/CFS. They should help the patient to plan activities to avoid post-exertion malaise (PEM), though there are times when PEM is an acceptable outcome in order to accomplish something.

Communication is central to successful caring relationships and to effective team working. Listening is at least as important as what the HCP may say.

It is essential for there to be, 'No decision without me.' Listen to the patient; this disease has no clear natural history, but listening implies trust. Take time to hear and interpret — to help the patient make sense of his/her experience. Seek clues about the 'former' person; people with severe ME often have to redefine themselves. Validate the individual, who is often socially isolated from family, friends or workplace.

Courage enables HCPs to do the right thing for the people for whom they care, to speak up when they have concerns. It means that HCPs have the personal strength and vision to innovate and to embrace new ways of working. However, it is the person with ME/CFS who needs the most courage. He or she may face social isolation, loss of role and identity, relationship breakdown and poverty. The HCP needs courage to visit essentially as a voyeur, often impotent to change the situation.

It was so refreshing to hear Caroline's talk, especially after the brilliant presentation given by Dr Eliana Lacerda in our AGM in 2019, when everything was normal and meeting face-to-face was an unknown privilege for us all.

Caroline was supposed to answer questions for about 15 minutes but she actually carried on for 30 minutes. She was impressed to hear a member of the Group who had been ill for more than 50 years. Other members suggested to build a room for him at the Biobank and keep him as a proper living sample. She was also thanked for being in the panel reviewing the NICE guidelines and fighting our corner. These thanks were extended to Dr Nacul and other members of the Cure ME team involved.

We thanked her for giving us such a great update from the CureME team's research. She was lucky for only needing to press a button in order to leave the meeting; otherwise, she probably would have been kidnapped by a tired mob!

Rules For Having ME Successfully

Some handy advice from the Shropshire and Wrekin ME Support Group.

* * *

- ★ Do not consider having ME unless you have a downstairs toilet.
- ★ In order to have ME successfully you should acquire a cleaner, gardener, cook and a general handyman. If this is impossible, you should find a rich, devoted, non-talkative partner with few outside interests.
- ★ It is essential that you budget and plan for ME as you will require an answer-phone, tumble dryer, dishwasher and many other supposedly 'luxury' items.
- ★ It is advisable to get rid of dependent children (unless they are very helpful) and to ask elderly relatives not to have any major crises during the course of your illness.

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- ★ Pets are a help, but they must be self-expressing and quiet. Furriness is a comfort if you have no allergies.
 - ★ All visitors should be advised to bring their own food (and some for *you* too). Overnight visitors should bring bed linen and take it home to wash.
 - ★ Patients should buy a new dressing gown fit for public viewing.
 - ★ Before embarking on this illness, the would-be patient should make a badge which says 'Looks alright, feels awful', and print a selection of explanatory leaflets giving details of the illness.
 - ★ Copies of the latter should be carried and distributed on all possible occasions, to protect from any misunderstandings, ignorance and downright nastiness.
 - ★ The person with ME (as the most restricted member of the household) should establish absolute authority over the TV remote control.
 - ★ The person with ME should let it be known that his/her needs will change from day to day without notice, and family members who help inappropriately will get their heads bitten off.
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The Needs for Better Fibromyalgia Services

Louis Morris of the National Health Executive explains how a new study shows the need for better fibromyalgia services

* * *

The results from two national surveys polling both health professionals and people living with fibromyalgia (FM) have appeared. The two surveys, part of the PACHND study, aimed to glean information about the best treatment courses for the condition, its management and its diagnosis, with one focusing on NHS professionals dealing with FM patients (survey A) and the other zoning in on those who have been diagnosed with the condition for more than 16 years and have opted to use non-NHS services (survey B).

Survey A garnered 1701 responses, whilst 549 individuals provided feedback to survey B. The results of the study revealed that the biggest perceived unmet need in the NHS for FM patients is simply the sheer lack of services. Across the acquired qualitative data, three recurring themes emerged.

- ★ A troublesome label.
- ★ A heavy burden.
- ★ A low priority.

The surveys also indicated that NHS services are 'highly disparate' for FM patients, with very few health professionals reporting accessible treatment pathways in their areas.

These patterns informed the research, providing important insight into the limited access potential fibromyalgia patients obtain in the health industry in the UK.

The diagnosis of FM was found to be variable within NHS services, with pharmacotherapy and just education being the main avenues in which the NHS treat and manage the condition.

The study concluded that the issues present across the NHS, as well as the dearth of FM services, include a potential bias towards individuals with self-diagnosed FM, GPs finding problems with getting secondary care involvement for patients, and a distinct lack of mental health services for those with FM.

The full article can be found on the National Health Executive website blog: <https://tinyurl.com/4zx8hu6s>.

Dr Charles Shepherd of the ME Association added:

These are the results from what is probably the largest ever UK survey of health professionals' attitudes to fibromyalgia along with the treatments and services that the NHS provides (or should be providing) for people with FM.

There is clearly a lot of clinical overlap between FM and ME/CFS and some people with ME/CFS have what I think is best described as a fibromyalgic component to their ME/CFS.

When it comes to treatment for FM, exercise programmes are often recommended, and there is a resistance from some health professionals to use prescription-only pain killers.

Finally, it is strange to find that there still isn't a NICE guideline on fibromyalgia.

NICE ME/CFS Guideline: Information for GPs

The Sheffield ME and Fibromyalgia Group (www.sheffieldmegroup.co.uk) has drawn attention to the 'Information for GPs' advice in respect of the revised NICE Guideline for ME/CFS, and we reproduce it below.

* * *

Key recommendations for your practice to be aware of:

- 1) The diagnostic criteria have been updated — these symptoms should persist for over three months, though their severity may fluctuate.
 - i) Debilitating fatigue, worsened by activity.
 - ii) Post-exertional malaise after activity which is delayed, disproportionate and has a prolonged recovery time.

- iii) Unrefreshing sleep.
- iv) Cognitive difficulties.

A timely diagnosis in primary care is important so that basic self-management of symptoms can begin early to avoid any worsening of the person's condition.

- 2) Named person: 'Give adults, children and young people with ME/CFS and their family or carers (as appropriate) a named contact in their primary care and/or ME/CFS specialist team.'
- 3) Review: 'Offer adults with ME/CFS a review of their care and support plan in primary care at least once a year, and children and young people a review at least every six months.'
- 4) New symptoms: 'Evaluate and investigate any new symptoms or a change in symptoms and do not assume they are caused by the person's ME/CFS.'
- 5) It is now advised that activity levels should be only increased if this does not lead to an exacerbation of ME/CFS symptoms, and so should not be done by fixed increments. 'Graded exercise therapy' (any incremental formula increase) should not be offered.
- 6) Some people need their care provided flexibly, for example, telephone consultations, online or home visits.

The guideline also specifically acknowledges that people with ME commonly experience 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.

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 been doing some embroidery, and on the right is her latest work, a delightful flower pattern.

██████████ has (finally) completed the introduction to the collection he has compiled, *Isaac Deutscher and his Critics*, an extensive array of critical essays on the famous Polish historian written by a wide range of authors dating back to the late 1940s. ██████████ has scanned, checked and annotated all the essays, and hopes to send the material to the publishers before long.



██████████ has continued with her painting, and has produced some new ones, including these beautiful stones. Lois can be contacted at ██████████, if you're interested in her artwork, and some of her work is for sale.

██████████ finds that doing jigsaw puzzles helps with her ME symptoms. Here is one that she recently completed.



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

ME and Corona Virus: Similar Impact on the Brain¹

Studies show that up to 43 per cent of people infected by SARS-CoV-2 do not recover fully and develop Long COVID in all cohorts, even in young adults,

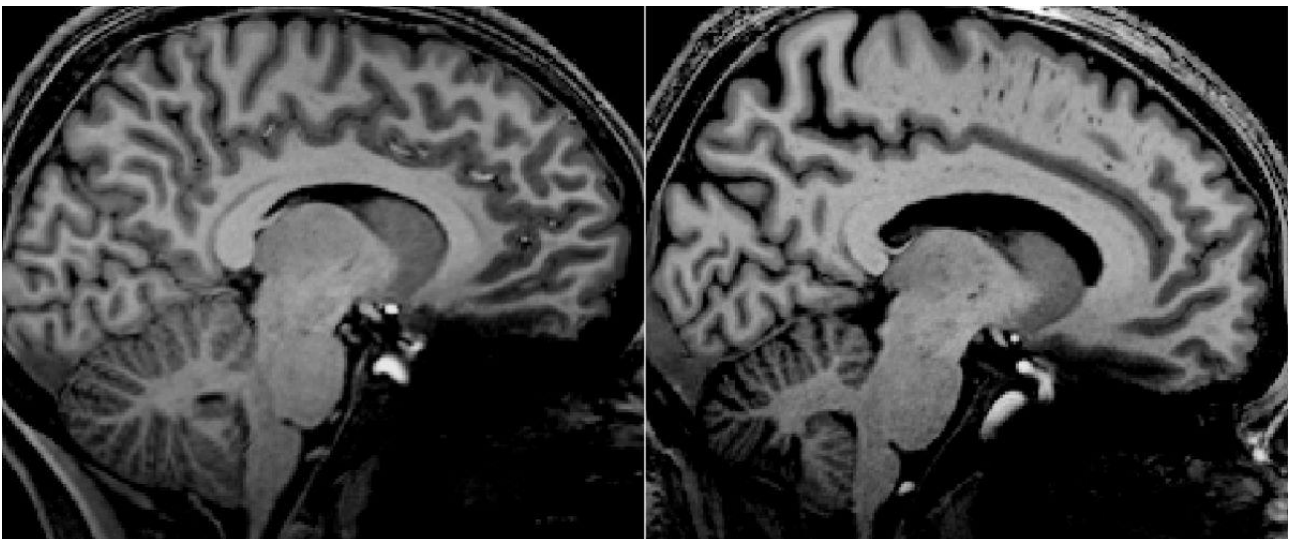
¹ Adapted from <https://news.griffith.edu.au/2023/03/14/worlds-strongest-mri-investigates-covid-and-myalgic-encephalomyelitis-chronic-fatigue-impacts-on-the-brain/>.

students and children. Recent studies showed that between 13 and 58 per cent of Long COVID patients show such symptoms as brain fog, fatigue, pain and autonomic dysfunction, which are similar to those experienced by ME/CFS patients. In view of these similarities, researchers at the Griffith University in Australia used an ultra-high field MRI (7 Tesla) scanner in a pioneering study to investigate the effects of COVID-19 and ME/CFS on the brain structure — with remarkable results.

Dr Sonya Marshall-Gradisnik, Director of Griffith's National Centre for Neuroimmunology and Emerging Diseases, said that the purpose of the study was to demonstrate the potential consistencies between the ME/CFS and Long COVID patients: 'We primarily used the 7T MRI to research the brainstem and its sub regions as it helps to resolve brain structures more precisely to discover abnormalities that other MRIs aren't able to detect.'

Lead author Dr Kiran Thapaliya said that the scan showed that the brainstem was significantly larger in ME/CFS and Long COVID patients compared to those who did not suffer from the same ailments:

It also showed similar volumes of the brainstem in patients which could be the reason Long COVID patients exhibit all common core symptoms of ME/CFS. We also discovered smaller midbrain volumes were associated with more severe breathing difficulty in ME/CFS and Long COVID patients. Therefore, brainstem dysfunction in ME/CFS and Long COVID patients could contribute to their neurological, cardiorespiratory symptoms, and movement disorder.



MRI scan of a brain showing a patient with Long COVID on the left and ME/CFS on the right — note the similarities.

The research was funded by the Stafford Fox Medical Research Foundation and ME Research UK. The full report, *Brainstem Volume Changes in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Long COVID Patients*, can

be found on the Frontiers in Neuroscience website at <https://www.frontiersin.org/articles/10.3389/fnins.2023.1125208/full>.



Simple Recipes – Keema

Here's a very nice Indian dish. It's enough for two people.

Ingredients

- ★ One onion, finely chopped.
- ★ Three or four cloves of garlic, finely chopped.
- ★ Half a pound (250g) beef or lamb mince.
- ★ Tin of chickpeas or similar pulses.
- ★ Spices — four cloves, four green cardamoms, 12 peppercorns, one two-inch cinnamon stick, one bay-leaf, three teaspoons each ground cumin and coriander, one teaspoon each ground turmeric, ginger and chili; one tablespoon of chopped fresh coriander.
- ★ Oil or ghee, salt and water.

Cooking

- ★ Heat the oil or ghee in a pan; add the cloves, cardamoms, peppercorns, cinnamon and bay-leaf, stir for a minute or two.
- ★ Add the mince, stir-fry until browned, ensure that there is no clumping of the meat.
- ★ Add the other spices and salt, stir-fry until the meat is cooked through.
- ★ Add the chick peas (or other pulses) and sufficient water to cover the mix; simmer for half an hour (more if you wish) until the mix is fairly dry.
- ★ Remove all the whole spices; stir in the fresh coriander.

Serving

- ★ Serve on a plate with boiled rice or wrapped in a chapati or similar type of thin flat bread.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.
A lot more than just being "tired"

ME/CFS (represented by a blue ribbon icon)

Headaches

IBS
 Nausea, bloating, cramps, constipation. Made worse with certain foods, sometimes even bland food. Heartburn and indigestion also

Heat/cold intolerance
 Temperature dysregulation, heat intolerance and cold intolerance are common

Low blood pressure
 Standing too long will often result in dizziness

Post-exertional malaise

Insomnia
 Trouble falling asleep or staying asleep

Palpitations

Internal vibrations
 Likened to standing near a washing machine on spin from a fair distance away. Particularly felt in arms and legs

Sore throat

Muscle weakness/pain
 Muscle aches, heavy limbs - like wearing a weighted body suit

Brain fog
 Confusion, inability to think clearly. You know what you're trying to say is there somewhere, but just out of reach

"Spaceyness"
 Better described as feeling drunk. 'Not with it.'

Shortness of breath
 Worse during a 'crash' and as the day progresses

Nausea

Multiple sensitivities
 Light, sound, touch, foods, odors, medication....

Emotional/psychological symptoms
 Anxiety, Depression, mood swings, excessive irritability, overreaction

Fatigue
 Utter exhaustion worsened by exertion (exertion can mean a short walk or having a shower)

Shantel Palmer

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 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 online 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	[REDACTED]	[REDACTED]
Membership Secretary	[REDACTED]	[REDACTED]
Committee Member and Group Library	[REDACTED]	[REDACTED]
Committee Member	[REDACTED]	[REDACTED]
Social Secretary	[REDACTED]	[REDACTED]
Twitter	[REDACTED]	[REDACTED]
Newsletter	[REDACTED]	[REDACTED]

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

Facebook	[REDACTED]	[REDACTED]
Project Coordinator	[REDACTED]	[REDACTED]
Interview Tape Recorder	[REDACTED]	[REDACTED]

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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