

# Richmond & Kingston

## ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

# NEWSLETTER

**No 2, 2023**

**Inside** — [REDACTED]'s Ten Questions — Severe ME Week — Howes-Goudsmit Prize for Caroline Kingdon — Simple Recipes — And More...

## **Old Clichés Never Die?**

The Oxford NHS Foundation Trust has found itself under criticism for an advertisement it issued for an 'exciting opportunity', a clinical psychologist post in its ME/CFS and renal transplant services. Two paragraphs of the job description read:

To communicate effectively, empathically and clearly with team members and other medical professionals regarding psychological or medical matters which will regularly be highly complicated... and which may require managing difficulties in understanding (such as cognitive deficits, or unconscious denial of psychological conflicts), or overcoming communication difficulties with patients *who are hostile, antagonistic, highly anxious or psychotic*.

In carrying out the duties of the post, to cope with and manage *challenging behaviour* at times, including *verbal abuse and risk of physical aggression* (for example from people with behavioural problems or enduring mental illness).

**Helplines Information: See Page 14**

Just look at the words I've emphasised. Are people with ME *really* 'hostile, antagonistic, highly anxious or psychotic'? Do health professionals dealing with us *really* face 'verbal abuse and risk of physical aggression'?

We all have days when we're additionally fatigued and thus a little ratty, but of the many people with ME I've known over the years, none has to my knowledge ever been 'antagonistic' or 'psychotic' or has yelled 'verbal abuse' or threatened 'physical aggression' against even the most obdurate health professional.

The Oxford Trust has stated that the offending words 'are not specific to people with CFS/ME but instead are part of a general skill set that clinical psychologists are expected to have should these issues arise'. Dr Charles Shepherd of the ME Association rejected this reasoning, stating that he is 'well aware of the way in which patients can behave when they are distressed, confused or angry', and adding that any health professional in that field should already be well aware of this and know how to deal with it. Whilst there are areas where such a warning is valid, Dr Shepherd continued:

I have worked with people who have ME/CFS for over 40 years — some of whom are upset and distressed by the lack of care and support they have been given by health professionals. During this time I have never had to deal with anyone suffering a psychotic episode or who was been physically aggressive. In fact, most people with ME/CFS are far too unwell to be physically aggressive.

On that basis, he concluded: 'I do not believe that it is necessary to use this sort of language in a job description relating to your ME/CFS referral service.'

However, I wonder if the wording was not just the result of the Oxford Trust's following a job description template, but the result, perhaps unconscious, of the influence of the psychosomatic 'it's all in your head' school of opinion and their long-running insinuation that people with ME have a tendency towards hysteria and violent outbursts. This they base upon their insistence that ME is essentially a psychological problem and that we're just imagining that we're ill, and that our refusal to accept their analysis and prescriptions leads us to abuse or threaten them.

It is true that members of the psychosomatic school have been the occasional target of intemperate responses by people with ME who have become angered by their constant refusal to take seriously our conviction, based upon experience (and recently confirmed by the new NICE Guidelines), that ME is a physiological illness. Whilst I don't condone such behaviour, I also think that it has been blown up out of proportion. The psychosomatic school has managed to get us all branded because of the desperate actions of a tiny minority, and it seems that this may well have seeped into the consciousness of some health professionals.

One of the key concerns of the Department of Health and Social Care's new Delivery Plan for ME is the use of language and the way in which health

professionals have failed to empathise with people with ME. The Oxford Trust's advertisement and their excuse for its terminology show all too clearly the work that needs to be done in this respect.

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## **Caroline Kingdon Wins the Howes–Goudsmit Prize**

The ME Association's Howes–Goudsmit Prize is an annual award of £5000 created from a very generous donation given by Dr Ellen Goudsmit, a disabled



**Caroline Kingdon**

scientist who helped to create awareness of ME in both the UK and the Netherlands, and who has studied the disease for over 40 years. It was named the Howes–Goudsmit Prize after Mrs Sandra Howes, a board member of the ME Association who had severe ME and spent years writing about the disease, and the late Mrs Felicie Goudsmit, a carer who became very familiar with the many challenges of dealing with severe disability.

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 (LSHTM), delivered

an excellent speech to the R+KME Group's last AGM in October 2022. We felt particularly touched when she spoke about what she has learnt from visiting people with ME/CFS. She defined 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. She said that many patients had barriers to be negotiated, as they were alienated from statutory healthcare services, although some were well connected through social media and often had more knowledge of ME/CFS than the healthcare practitioner. She mentioned that it was a challenge for practitioners to visit people with ME/CFS because there was no effective treatment, it necessitated great wisdom, compassion and skill, and they may also have felt vulnerable as patients often knew more about the disease.

The ME Association awarded Caroline the Howes–Goudsmit Prize in recognition of her work visiting severely affected people to collect blood samples and clinical data for vital research. Dr Charles Shepherd, trustee and honorary medical adviser from the MEA, said:

We are incredibly proud of the work that Caroline has done visiting severely affected people to collect blood samples and clinical data for vital research. We would like to thank everyone who welcomed her into their homes knowing that participation often made symptoms worse but whose desire to support research was so strong.

Caroline was a member of the NICE guideline committee responsible for the much-improved 2021 NICE Guidelines on ME/CFS which includes new recommendations for healthcare professionals about managing people with Severe and Very Severe ME/CFS.

Her empathy and expertise made her the winning candidate for this year's award, and we are delighted that she will be continuing the work of the UK ME/CFS Biobank.

On receiving the award, Caroline said:

I am honoured and delighted to accept this award, on behalf of all those I have met with severe ME, who have graciously welcomed me into their homes. Disbelief and stigma often alienate people with ME from the medical support they need, and frequently cause estrangement from family and friends.

Each of the individuals I have visited has patiently explained how the disease impacts upon their lives, and the strategies they use to manage it. These visits often draw on their last reserves of energy, and we know that a visit can negatively impact a participant for hours, days or weeks afterward; nonetheless each person has still given their time, expertise and energy to enable life-changing, biomedical research.

I would like to acknowledge the dogged determination of the rest of the team at CureME led by Eliana Lacerda and Luis Nacul; they are passionate about the need for robust research and have driven the UK ME/CFS Biobank with scientific and ethical rigour. I hope to use this award to share the experiences of people with severe ME, and to continue educating healthcare professionals about its impact. I would like to thank the Board of Trustees for this tremendous validation of the work of the CureME team.

Fernando of the R+KME Group Committee was one of our members who was visited by Caroline. He said:

Having her at home for the collection of blood samples and research has been such a privilege. She is the kind of practitioner we all need around: caring, cheerful and to the point. At the end of each appointment and although I was feeling tired, instead of leaving my house she actually had to escape to avoid being trapped with me talking a lot while she's humming the song 'Fernando' from ABBA!

The R+K ME Group would like to thank Caroline for all her great work and research on our illness, as well as to Dr Eliana Lacerda, who has also delivered speeches to our AGMs, to Dr Luis Nacul and to the whole CureME team at the LSHTM.

For donations to the CureME Research Team at the LSHTM, please follow the link <https://cureme.lshtm.ac.uk/donate-to-cureme/>.

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## **Meetings with Healthwatch Kingston**

As mentioned in a previous edition of our newsletter, some colleagues from Healthwatch Kingston, and 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. It can be reached at <https://www.healthwatchkingston.org.uk/advice-and-information/2022-05-26/all-about-myalgic-encephalopathy-me-and-fibromyalgia-services>.

We also mentioned that they 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 would approach the NHS Integrated Care System — previously called the Clinical Commissioning Group — and the Council to request more provisions for us. A total of 25 people responded to the survey.

██████████ was invited to a meeting with Healthwatch Kingston on 28 February 2023 to review their findings and to another on 15 March, which included two members of our Group (██████████ and ██████████) living in the borough, in order to gather their opinions and views and give their feedback on the information Healthwatch would like to present to the NHS.

We thank the whole team at Healthwatch Kingston for carrying out this important work of helping patients with ME/CFS to obtain the services that are needed.

Healthwatch Kingston's annual report contains a small mention of ME on page 12. You can find it at <https://www.healthwatchkingston.org.uk/report/2023-06-28/healthwatch-kingston-annual-report-2022-23-together-were-making-health-and-social>.

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## **Postcode Society Trust's Grant**

The R+KME Group received a grant of £500 provided by the Postcode Society Trust and Localgiving via their Magic Little Grants scheme. The Postcode Society Trust is funded by players of the People's Postcode Lottery.

The People's Postcode Lottery is a not-for-commercial-gain organisation owned by the Novamedia/Postcode Lottery Group, the creators of the post-code lottery brand. This group has been operating since 1983 with the goal of contributing to a better world through the operation of charity lotteries, media and publishing activities. Its sole objective is to support charitable and social initiatives across the world.

With a belief that the world benefits from strong social organisations, the mission of the People's Postcode Lottery is to help raise funds for charities and good causes and to increase awareness of their work. Going beyond grants, the People's Postcode Lottery understands the importance and potential impact that unrestricted, flexible and long-term funding can bring. Licensed by the Gambling Commission, the People's Postcode Lottery manages charity lotteries for 20 Postcode Trusts.

The award received by our Group is to help pay for our annual subscription to Zoom. With this subscription, all our online meetings can be accessed by pressing just one link or by introducing one meeting ID and password, facilitating the admission for all our members, especially the ones with tremors or shaking hands as a consequence of our illness.

Online social meetings are nowadays crucial to the reduction of isolation among our members. Many of our members have taken part on them, whether they be general coffee or pub meetings, or more specialised ones, such as silent reading, crafting or mindfulness meetings. If you're feeling under the weather or simply not too keen on online meetings, you could easily join with your camera off and your microphone on mute. In this way you could listen to others' conversations and feel that you are part of a community facing your same challenges, and with empathetic people completely understanding your personal situation.

We are grateful to Localgiving and the players of the People's Postcode Lottery, which is funding the Postcode Society Trust, for their support, and we wish them all the best with their endeavours.

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## Ten Questions

This time answered by ██████████.

- 1) **How long have you had ME?** I was diagnosed in 2015 but I believe I have had it since 1990–91 after one of a couple of mystery illnesses. I would get strains of it coming back over the years, and my symptoms have come on very gradually, until I reached a point where I knew something was wrong. When I registered with my current GP in 2014, she asked if I'd ever considered I might have ME/CFS, and a few months after that, I received a diagnosis.

- 2) **What was the trigger that started it off?** I had a couple of short periods of illness in 1990 and 1991 and, on hindsight, it's those that really triggered it off. I've had quite a stressful life since my teens (it took a therapist to tell me that!) and a very boom-and-bust lifestyle, and the consistent levels of stress for many years has really contributed to it, and sustains it, unfortunately.
- 3) **What is the worst thing about having ME?** The fact that I still have the same impetus to do things and am forced into recognising my limitations. Even things I used to love to do — lots of acting, writing, singing, walking, concerts, theatre — I just cannot do anymore due to lack of energy and focus, and due to trying just to cope with everyday life.
- 4) **Has anything good come of it?** I like to look at the positive side of things but honestly, no. I feel like I am being robbed of life and potential.
- 5) **What treatment (prescribed or alternative) has helped the most?** I suspect that if I focussed more on mindfulness and meditation they would help. I know people sometimes mock this idea but I do believe it can help. I am trying to watch my diet and get more hydrated and get more fresh air. These aren't as easy as they sound! I'm currently interested in gut health, and will be looking more at that at the moment.
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Graded Exercise Therapy! I was never the most exercise-y kind of person, but every now and again I'd get the urge to do a bit of exercise for a period. It's one of the most frustrating things because on one level, yes, exercise does help with low mood, low energy and stamina, and circulation, etc, etc. But that very sensible logic just doesn't work with people with ME/CFS. I wish it did. We're not like this because we're lazy.
- 7) **What do you like doing on a good day?** Catching up with things. I just love peace and quiet and spending time with my pets. If I knew there wouldn't be a pay-off I would love to go for a long walk with my camera, stop off a couple of times for coffee and a treat. Do a bit of writing, maybe.
- 8) **Do you have any tips for getting through a bad day?** I've had to learn to be patient. (I've *always* been known for my lack of patience!) If my body is not going to do what I want it to do, I just have to wait it out. Ideally in my bedroom, which is darkened and quiet. I have all my favourite TV shows and films set up in the bedroom, FIVES sets of wireless headphones all charged up within reach, and my phone nearby with relaxation apps, puzzles, music, white noise and games on them. If I can manage to set them up (or if my other half does it), there will be flasks of hot and cold drinks and some snacks in case I get hungry.
- 9) **What is the worst thing anyone has said to you?** Compared to many I think I've been lucky. No one has said anything bad to my face. There was a psychiatrist who sat throughout the whole session looking at the internet, had never heard of ME/CFS and had no idea of what it was, and he didn't

make eye contact with me at all. In the report back to my GP (and it was a desperate act that had taken me to that appointment), he essentially said that I thought I was having a midlife crisis. Words I would never have used. So it was really that lack of interest and dismissiveness that angered me. Usually people (medical and otherwise) are interested. I do get some well-meaning but useless advice at times. I also get people asking what I did to my leg (!), or asking why I use a stick... Usually, I don't mind as it's an opportunity to educate people, but sometimes I'm not in the mood for it. I think it's kind of rude to ask, really.

- 10) **And the best?** Oh! As I said in the previous answer... It's nice when people are interested. I've met a few people (not many) who are familiar with it, or might have conditions with similar symptoms, and they've been great. The one that stands out most is a young make-up artist I met on a job, who was in remission, and she told me how she'd gone from being in a wheelchair to where she was then. It was interesting and inspiring. It gave me hope. Also, she made sure I sat and rested at every available opportunity. This was four years ago, and I've taken her to every job I've done since. I get her in my head telling me to rest even though I don't think I need to, and I'm less shy about asking to sit down at work now.

Extra questions:

- 11) **Where would you like to be now?** I cannot bear noise. I could tolerate everything else with this condition if I could only live in peace and quiet. But I seem to live in the noisiest flat possible. There is constant noise and it is really hampering any attempt at recovery. So... Just anywhere quiet. Quiet, quiet, quiet. Quiet.
- 12) **Tell us a joke/mantra/quote:** Well my favourite mantra was always Benjamin Franklin: 'Dost thou love life? Then do not squander time, for that is the stuff life is made of.' I think I need to change the boundaries of what that means these days, but it's still engrained in me!
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## Severe ME Week

This year's Severe ME Week took place during 7–13 August. Around a quarter of the people in Britain with ME have Severe ME symptoms. Whilst people with Severe ME know all too well what this entails, it's worth describing its impact upon their lives, as many people are unaware of what living with Severe ME is like.

People with Severe ME are often house-bound, even bed-bound, and many require 24-hour care. Many are hypersensitive to light or noise. Quite a few find themselves socially isolated and as a result can suffer mental health problems.



Anna of *ME, Myself and I*, writes:

I want to be able to brush my teeth, everyday. I want to be able to say 'yes' to going out in the car with my husband. I want to be able to make something more than toast for myself. I want to be able to stay out of bed past eight o'clock in the evening without its affecting my ability to fall asleep.

I want to be able to socialise on-line (the only place I can often socialise) without having to impose my own limitations on how long I can reasonably be on-line for. I want to change the bed for clean, fresh sheets.

I want to be able to pop out to the shop when I need something. I want to wake up without doing so feeling like I've already overdone it. I want to be able to read a book. I want to be reliant only on myself.

I want to get washed and dressed everyday. I want to look forward to seeing my friends, without having to plan each visit so carefully. I want to post my own letters at the post-box that's 'only' 50 metres away.

I want to give, rather than constantly take. I want to talk about these things without being told 'At least...', or that it could be worse. I want to do these things and more without effort or struggle or repercussions.

Here are just some of the physical and mental symptoms of Severe ME, as compiled by Stonebird. There are a lot more listed on the Kirklees and Calderdale ME Group's Facebook page <https://www.facebook.com/groups/1862842720602899/>.

Severe ME is a hellish experience that you live and endure without treatment, cure or respect.

Severe ME is being totally ill, all the time.

Severe ME is finding that everything normal is out of reach.

Severe ME is having all the things you love taken away from you.

Severe ME means that your mind lives in a sea of fog, confusion and emptiness, struggling to both process and understand incoming information.

Severe ME is spending your life predominantly sitting in a chair unable to move or function, or in bed, predominantly paralysed.

Severe ME is being always in constant pain, that everything you try to do hurts you on some level somewhere.

Severe ME is being unable to manage without help, all day long.

Severe ME is having no energy.

Severe ME is your mind not working.

Severe ME is being unable to read.

Severe ME is being unable to hold anything.

Severe ME is feeling dizzy and disoriented most of the time.  
Severe ME is being unable to speak on the phone.  
Severe ME is finding that going to bed or remaining in bed makes you feel even more ill.  
Severe ME is discovering that there is no possibility of rest, ever.  
Severe ME is being unable to see people because they make you more ill, because you are so hypersensitive.  
Severe ME is finding that any noise irritates to distraction.  
Severe ME is not knowing what to eat that won't hurt you.  
Severe ME is being unable to find any clothes that don't itch or hurt you.  
Severe ME is being unable to travel without torment, if at all.  
Severe ME is being unable to bear being touched because of the pain and irritation that it causes.  
Severe ME is finding that anything you do will lead to worsening pain, paralysis and numbness.  
Severe ME is finding that your hypersensitivity is increasing.  
Severe ME is never going on holiday, or to social or family events.  
Severe ME is struggling to breathe.  
Severe ME is struggling to eat, because chewing is exhausting and swallowing is dangerous when food gets stuck.  
Severe ME is numb eyeballs and itchy, burning eye pain and scratchy, dry eyes.

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## **Jennifer Brea's *Unrest* Now on YouTube**

This award-winning documentary is finally available free of charge on YouTube. Jennifer Brea's *Unrest* describes a personal journey from patient to advocate to storyteller. Jennifer is 28 years old, studying for a PhD at Harvard, and months away from marrying the love of her life when a mysterious fever leaves her bedridden. She films her darkest moments after ME has brought her previously life to an abrupt and alarming halt.



Brea's wonderfully honest and human portrayal brings us into the hidden

world of millions who the medical world have abandoned, as she looks for answers and fights for a cure. It's a good film to show your friends and family — and to health professionals who still think that ME is 'all in our heads'!

It's available here: <https://www.youtube.com/watch?v=XOpyLTyVxco>.

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## **Group Online Zoom Meetings**

The R+KME Group runs several types of online meetings for members. Each month we have two two-hour general coffee meetings, one starting at noon, the other at two o'clock in the afternoon; one 'pub' meeting starting at six o'clock in the evening; and two mindfulness meetings, one crafting meeting and one silent reading meeting, all starting at four o'clock in the afternoon. We are also starting a monthly Haiku meeting, starting at half-past two

Around half of the Group's members have attended meetings since we started running them. If you haven't yet attended one of our meetings, why not have a go?

Details of the dates of all our meetings can be found on our website at <https://www.richmondandkingstonmegroup.org.uk/events-diary>. An e-mail reminder is circulated a day before each meeting, and this includes instructions on how to gain access to it.

If you would like to join our meetings, please contact [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. We are very grateful to [REDACTED] for all her hard work in coordinating these meetings.

Don't forget that we're running one 'face to face' meeting each month; again, details are at <https://www.richmondandkingstonmegroup.org.uk/events-diary>.

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## **ME Awareness Day at Sutton Hospital**

The South West London and Surrey ME/CFS Specialist Service, formerly the Sutton Chronic Fatigue Service, held a service awareness afternoon on Wednesday, 10 May 2023 to mark ME awareness week. The R+KME Group were amongst those invited to attend the meeting, which was held at the Malvern Centre in Sutton Hospital, part of Epsom and St Helier Hospitals.

Attendees had the opportunity to hear about the services provided, talk to the whole Specialist Service team, ask questions and socialise, while enjoying a nice cup of tea and some biscuits, or one of the impressive and very tasty cupcakes with 'ME' written in blue icing that were made by a member of the team.

Six members of our Group managed to attend and we thank the team at the Malvern Centre for organising the event, and for giving us the opportunity to spend a lovely afternoon with people who actually understand ME/CFS and can offer support to us and others with this illness.



## Rachel Hazlewood – The Cost of Living

I try to live my life — and then  
 I find I'm back in bed again:  
 Exhausted, drained, wrung out and weak;  
 Too tired to move; too tired to speak;  
 Too tired to lift my head — or blink.  
 The only thing to do is *think*.

I think about the life I had:  
 It breaks my heart, it makes me sad  
 To think of what I used to be  
 Before this illness — before ME.  
 I used to take it all for granted,  
 Being and doing whatever I wanted:  
 I could work all week and meet with friends and talk,  
 And don my boots and walk and walk...

I loved to walk. Oh Boy! Oh Man!

I'd walk up Snowdon, up Pen Y Fan,  
Cross Striding Edge and up Helvellyn.  
If I tried that now there'd be no telling  
What price I'd pay for the attempt:  
I guess I'd end up back here, in bed — unkempt.  
You might think I'm daft; or mad; plain crazy.  
It's all in my head — perhaps I'm lazy.  
There are no tricks, no hocus-pocus  
For us we must fine-tune our focus.  
Nowadays there's far too much to lose  
If I don't take the time to carefully choose.  
With this relentless illness in my life —  
Today should I be friend or sister, daughter, aunt or wife.  
Should I give my all at work — or stay at home,  
Feeling useless, worthless, abandoned — alone.  
Should I wash up, or Hoover, or do a small task in the garden.  
If I cancel plans with you I do beg your pardon.  
But when your life is touched by ME,  
You'll understand, you'll quickly see:  
Whatever I choose there will be a price to pay  
Tomorrow, if I choose too much today.

For you may think it's great to lie in bed  
All day, and rest and sleep and dream;  
But not for me — in pain, exhausted,  
To lie and think and silently scream...

From the Welsh Association of ME & CFS Support website, <https://wames.org.uk/cms-english/>.

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## Simple Recipes — Chicken Curry

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

### Ingredients

- ★ One onion, grated.
- ★ Three or four cloves of garlic, grated, or three teaspoons of garlic purée.
- ★ One cubic inch of ginger, grated, or three teaspoons of ginger purée.
- ★ Half a pound (250g) of chicken, raw or cooked, cut into fairly small pieces.
- ★ Tin of chickpeas or similar pulses.
- ★ Four or five tablespoons of thick plain yoghurt.
- ★ 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 ground turmeric, half a teaspoon ground chili.

- ★ 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.
- ★ Stir-fry the onion, garlic and ginger until they start to brown.
- ★ If using raw chicken, stir-fry it until browned, then remove and set aside.
- ★ Mix the yoghurt in a pot with the ground spices and salt, then gently stir-fry with the onions.
- ★ When the oil rises above the mix in the pan, stir the chicken into the mix.
- ★ Add the chick peas (or other pulses) and a little water to cover the mix; simmer for half an hour (more if you wish) until the sauce is fairly thick. Stir in another tablespoon of yoghurt if the sauce is too runny, or add some water if it's sticking to the pan, and simmer until the sauce is fairly thick.
- ★ Remove all the whole spices.

### **Serving**

- ★ Serve on a plate with boiled or pilau rice.

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## **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]

[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](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.

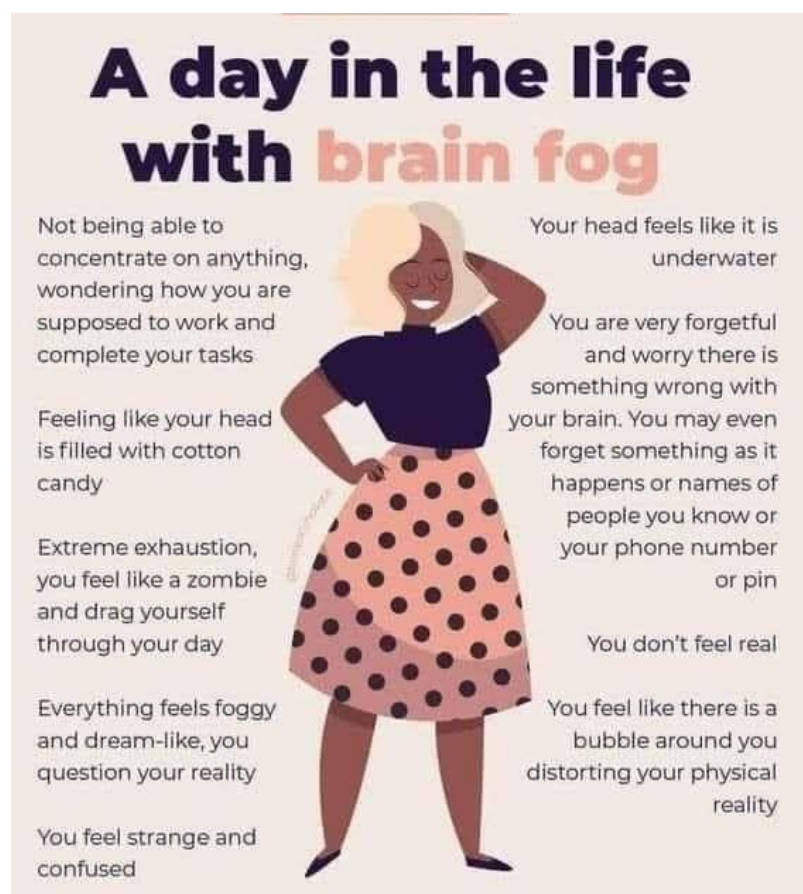
The ME Association runs ME Connect. It provides support for people with ME and those who live with or care for them. It is open every day of the year between these times: 10.00am to 12.00 noon, 2.00pm to 4.00pm, 7.00pm to 9.00pm. The telephone number is 0844 576 5326. There is an e-mail contact at meconnect@meassociation.org.uk.

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/>.

## 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 meetings 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.



<b>Richmond and Kingston ME Group Committee</b>		
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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