

Q&A with Caroline Kingdon

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Q+A with Caroline Kingdon, UK ME/CFS Biobank

- **Do you think there is a role for palliative care teams when meeting the needs of patients with severe ME?**

I am not sure that palliative teams are ideal for this role for several reasons. I worked in palliative care and while the presentation of someone with severe ME/CFS can be remarkably similar, palliative is defined as *of a medicine or medical care) relieving pain without dealing with the cause of the condition*. While there are currently no evidence-based treatments for ME/CFS, I believe that there is a need for multidisciplinary teams to better manage the disease, specialising in ME/CFS. Because people with severe ME/CFS are largely unable to attend hospital appointments, home visits will be imperative; while the symptoms may mirror terminal illness in some respects, it is a very different disease. I realise that there are currently few if any such teams in existence, but was heartened to read the NICE statement released in May [Impact on NHS workforce and resources | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#). The implementation of the guideline will inevitably take time, but we are optimistic for the future.

- **What do you think the impact of research into long Covid will have on ME? will it lead to greater understanding that ME is a physiological condition?**

I do think that Long COVID research will positively impact ME/CFS research. For example, an eminent consultant at UCL, with whom we are working has seen the very real physical impact of enduring symptoms of COVID19 in some of her colleagues (doctors, nurses, physios, cleaners); these seem to be similar, if not identical, to the symptoms of ME/CFS. There is great momentum behind Long COVID research that will, in time, also help to improve the care and treatment of people with ME/CFS.

- **What measures do you take when visiting someone with severe or very severe ME, for CureME, to avoid exacerbating their symptoms?**

Most appointments, either face-to-face or virtual, are ideally scheduled for after midday as many people with severe ME/CFS need to rest until then due to erratic sleep patterns. I try to ensure that my tone of voice and any physical contact with the patient is appropriate for someone seriously ill. and that questions are simple, requiring short answers.

I avoid smoky environment or the use of perfumes or fragranced lotions before I visit; some patients have requested that clothes are not freshly laundered because of the effect of fragranced detergents.

If I have any symptoms of a possible infection, I do not visit and when I go into the home of any person with severe ME/CFS, I remove my shoes and thoroughly wash my hands; in COVID times, I went fully masked, gloved, and gowned.

I only ask the patient to do things appropriate to their energy envelope and phrase questions so that they are simple and require short answers.

- **How do you take blood samples if the patient is in darkened room?**

I use the torch from my iPhone and make sure the eyes of the patient are shielded from the light.

- **What research have the blood samples you have taken for CureME been used for?**

The UKMEB has provided samples and data to many ME/CFS research groups in the UK, Europe, North America, Latin America, and the Middle East. There are publications ranging from immune activity in ME/CFS, creatine levels in severe disease to natural history of the disease and the value of measuring handgrip, to give just a few examples. The true worth of the facility is underlined not only by the publications coming from the release of samples but also because of the associated papers, which are widely cited in the literature.

- **From the research that CureME is doing and the wider ongoing research into Long Covid realistically, how long do you think it will be before the aetiology of ME is fully understood?**

We all wish we knew, but advances are being made all the time.

- **Do you think the new NICE guidelines mark a turning point for people with ME now that Graded Exercise Therapy (GET) has been removed?**

The new guideline makes clear that all patients diagnosed with ME/CFS in primary care require referral to a specialist team for multidisciplinary input and coordination of care. It sets new standards for health professionals to ensure people with ME/CFS can access the right care and support to help them manage symptoms and makes certain no treatment, including GET, that may cause harm is offered. We believe this is a real turning point for people with ME/CFS

- **What aspect of the NICE Guideline are you most pleased with?**

I believe that the guideline in its entirety promises to treat people with ME/CFS with compassion, ensuring safe care of the highest standard, delivered appropriately according to the needs of the individual.

- **What impact do you think they will have on NHS commissioning?**

Evidently there will be a need for resources to fund the recommended changes and this will take time, particularly when the NHS is challenged with record-breaking waiting lists for

diagnosis and treatment in many diseases. It is unfortunate that the guideline release has been ill-timed in this respect, but we remain optimistic that the momentum from ME/CFS charities and patients will ensure the commissioning to support their implementation.

- **What medical professionals do you think should lead the clinics?**

Some of us on the committee fought hard for physician-led clinics but understood that this might preclude the establishment of such services. I suspect that we will see people with different backgrounds leading services, though I believe that they would ideally be led by doctors.

- **What is the best approach individual patients can take to ensure health professionals implement the NICE Guidelines such as providing home visits to the most severely affected patients?**

All people with ME/CFS are entitled under the new guideline to see a specialist ME/CFS team and should have their management plan updated annually. They can hold their GP to this, although it will obviously take time to establish the required number of multidisciplinary specialist ME/CFS teams. Anyone offered GET should refuse it and bring it to the attention of the head of the health service provider, mentioning that the new NICE guidelines is very clear on this point.

We would like to thank Mrs Caroline Kingdon and the Cure ME Team for taking the time to answer these questions.