

## **Doing Research in Chronic Fatigue Syndrome with Chronic Fatigue Syndrome – Dr. Keith Geraghty**

My name is Dr. Keith Geraghty, I am an Honorary Research Fellow at the University of Manchester in the Centre for Primary Care. My main research interests are patient safety and harms, doctor-patient relations, medically unexplained illness and ME/CFS research. So how did I get involved in CFS research? Well, I am one of the estimated 250,000 sufferers of ME/CFS in the UK. There is no doubt that ME, or CFS, whether one illness or discrete conditions, are life changing conditions for many; but it's also very challenging from a research perspective, not just because the illness is enigmatic and complex, but because of many other factors, some of which I hope to articulate here, sharing my experience as both a CFS researcher and a CFS sufferer.

### **My CFS story**

I was a medical student in my 20s with no prior history of health problems when I became unwell with a viral illness. I had the usual symptoms of sore throat, swollen lymph nodes, and malaise. My general practitioner told me I'd recover, that "these things take time to leave the body", but as time went on, I just felt more fatigued, often coming home from ward rounds at the hospital, only to flop onto my bed wearing all my clothes, shirt, tie, and stethoscope. I would wake the next morning feeling just as tired as the day before. I'd scramble up and head out for another long day - and that cycle continued until my body just gave way. I was told I was suffering from exhaustion and anxiety. I certainly felt exhausted and I certainly felt anxious; I was anxious to return to my career and I was anxious to know what had possibly gotten me into this terrible situation.

When I first became unwell, my GP was kind and supportive. I was referred to an infectious disease specialist who told me I'd be back playing rugby in no time. However despite his optimistic outlook, I went from a fit healthy person who fully engaged in life, to mostly bedbound. I went from being an active young person, University Rower and Army Officer candidate, to being unable to walk more than a few metres. Despite my best efforts to get better, I did not return to my former self, I just remained in a quagmire of fatigue and pain. After rounds of medical investigations that could not find anything remarkable, my friendly doctors started to question my mental health, referring me to psychiatry. I didn't feel psychologically unwell, apart from feeling anger and frustration with my situation. However I found myself sitting before a psychiatrist who seemed to know very little about CFS. It was at this point, drained of energy and demoralised by fighting with physicians, I withdrew from my medical career to convalesce.

For a few years I could do nothing but suffer and survive, but eventually I began to regain some energy and I was helped along the way by many kind friends and lots of books, such as Andrew Weil's 'Spontaneous Healing'. I decided to do all I could to recover, including the usual regime of dietary changes, vitamins, yoga and so on. While I believe these things

helped, what helped most was just accepting my situation, pacing myself and giving my body and mind time to rest. I am far from fully recovered, but I have made considerable progress.

### **The road to CFS research**

Around 2008 I began reviewing CFS research, roughly starting with Ramsay's work at the Royal Free Hospital in London in the 1950s. I should mention that I was in the lucky position that I had completed much of my higher education prior to getting CFS, I had a PhD, masters, bachelors. I had been at medical school, and I had worked as a researcher at Imperial College London. I took on the challenge of reviewing the large body of research on CFS/ME. It quickly became apparent to me that this illness had been rather neglected, compared to other comparable conditions, and that the incumbent model of CFS, the biopsychosocial model, just didn't fit my personal experience and much of the model rested on theoretical assumptions, which just didn't make sense to me. I tried to keep an open mind and put myself in the position of a researcher reviewing the evidence.

At one point I went to meet with Prof. Baker, chairman of the committee that published the UK NICE guidelines on ME/CFS. I raised some concerns about the quality of the evidence, the lack of breath and the potential harms associated with some of the treatments proposed. I was surprised to find that Prof. Baker agreed that the guidelines were not perfect and the evidence was far from ideal. This was my feeling too: I had read a couple of papers a day, amounting to a couple of hundred papers a year. I was becoming very familiar with the literature, however I felt my skills of review needed some updating so I undertook a master of public health at the University of Manchester. At Manchester Medical School I began discussing my concerns about CFS research with academic mentors. I was fortunate that one professor liked my ideas and he offered me an opportunity to work with him. I found myself back in academia as an Honorary Research Fellow.

### **Research isn't easy, especially in CFS**

In 2014 I decided to change focus, from reviewing studies, to starting to write my own papers and designing my own projects. It was at this point I discovered just how difficult doing CFS research can be. I had heard of a new UK ME/CFS Research Collaborative and I sought to join, with the aim of connecting with other CFS researchers. It took me about a year and a half to be accepted as a member and to date I can't say my membership has brought about the networking I'd hoped for. I also searched long and wide to find other CFS researchers in the UK who might be doing work in the areas that most interested me: I struggled to find more than one or two dedicated CFS researchers. I sought counsel from senior academics at my host institution and elsewhere, but I was sometimes warned to "steer clear of CFS if I wanted a career in academia". Some colleagues suggested CFS is "too emotive a subject" and that, "it's too controversial a topic". I found myself debating whether or not I should take a salary and job doing primary care research, or to take the more risky and difficult road of CFS research. I decided to take a position at Manchester University that gives me the flexibility to continue my CFS work.

I think many junior researchers in CFS will face similar hurdles; being warned off, finding it difficult to connect with knowledgeable mentors, and finding it hard to publish papers in this controversial area. Luckily for me I had the support of the University of Manchester and I have begun to publish papers on CFS. I also found that junior academics are sometimes more amenable to new ideas and have the time to talk to you; so one strategy I have employed is to network with junior researchers.

I recently worked with a medical philosopher at the University of Leeds to write papers on harms in CFS and the ethics of consent in psychotherapy. I also generated a project proposal with researchers at the University of Coventry and Bournemouth University to investigate cognitive dysfunction in CFS. These collaborations came from simply asking others for help. I have also been in regular contact with a number of UK ME/CFS charities to talk about my research: charities usually have someone who is able to offer advice about taking CFS research forward. I think a key message for anyone looking to do CFS research would be don't be afraid to ask for help and cast your net as wide as possible. There are many brilliant academics out there, not all will have the time to help, but eventually you will find people willing to help and share expertise.

### **The future**

Today I find myself busy reading papers as usual, writing research grant applications, dealing with paper submissions and the review process; including attempting to convince editors and journals to accept my papers (all part of normal academic activities). I use every opportunity to connect with other researchers; I think this is a vital part of research, particularly in CFS where there are perhaps less researchers. I also really enjoy connecting with patients, I often share my draft papers with patients and ask for their opinions prior to submission – I think this is a model other researchers should adopt. I haven't conquered every barrier in CFS research and there are many, both personal and professional, but I am making progress, mostly through hard work and determination. In the next year or two I hope to publish more widely and establish myself as a leading CFS researcher in the UK. Maybe in the future I will be able to offer support to other CFS researchers who might be looking to come into this challenging research field.

**Dr. Geraghty is interested in collaborating with others on new or existing ME/CFS projects, especially in Europe but also elsewhere. He may be contacted at: [keith.geraghty@manchester.ac.uk](mailto:keith.geraghty@manchester.ac.uk)**