

Q&A with Dr Nina Muirhead

Miss Nina Muirhead is a dermatology surgeon specialising in cancer. In 2016 she developed ME following glandular fever. For the majority of 2017 and early 2018 she was virtually bed bound and needed care. At this point she realised the extent of the lack of knowledge about ME from doctors. She champions educating all healthcare professionals about ME. Nina now describes herself as moderately affected and is able to work two and a half days a week.

What do you feel helped you to improve, particularly to the point where you are now working part-time as a surgeon?

The main thing that helped was being lucky that my ME was not severe for too long. I also had the right advice from my GP to rest and pace. I am very fortunate to have had the support to be able to rest, and I know for some that is not possible. Practical things were vitamin D and B12 supplements, antivirals, wheelchair, healthy diet, adequate hydration, care and support from family, friends and my employer, both the trust and the team. I know some people have done all the right things and are still severely ill, so there is an element of luck and genetics. The disease severity can have very little to do with what you do or don't do. It is important to maintain hope and not overstretch your energy capacity – in-fact do about half of what you think you can do.

From your 'lived experience' you have been able to put across what it's like to live with ME at the same time as being respected as a doctor. Prior to getting ME, were you taught about ME and if so what?

I didn't know much about ME but had wrongly assumed there was a mental health, depression and deconditioning aspect to the disease. I was shocked to experience being my normal self yet so incapacitated and feeling so physically weak and ill. As regards the diagnosis it took months to realise it was ME. I remember lying in bed for about a month trying to comprehend how this was such a common and misunderstood disease. I thought either I had something rare, or the medical profession had got it wrong. It was almost unbelievable to discover that it was the latter.

Why do you think some clinicians have preconceived ideas about ME as a psychological illness?

It's hard to imagine feeling this ill and looking well. It's also difficult to see how the patient is before and after the consultation. 21st Century medicine has developed such a strong evidence base and established biomarkers for other diseases. We need to use our skills of taking a good history and listening. Psychotherapists have previously controlled the narrative on this disease, and it is easy to understand why their disease theory is psychosocial and their cure is psychotherapy – that's the area of medicine that they have chosen to specialise in. Sadly the rest of the medical profession have let the psychotherapy theories dominate.

How do you envisage change happening to the attitudes of health care professionals?

I think it has been a shock and realisation for many healthcare professionals with Long Covid that there is such a denial, stigma and misunderstanding in the medical profession. Some have been utterly stunned and appalled to find themselves being labelled as anxious when they are clearly unwell. Long Covid is a large-scale health crisis and will be around for some years. I think that will bring change. The new NICE guidelines are an opportunity to initiate change. Updated education needs to be mandatory and top down. The other change that is needed is the trainers, teachers, medical school deans, Health Education England and education boards of the Royal Colleges need to update their knowledge. It is a huge paradigm shift to recognise that there is a disease which is made worse by exercise. It's also embarrassing for the profession to admit they got it wrong, apologies will be required. I am so sorry that I had it wrong.

Why do you think medical education around ME is so poor and what can be done about this both at medical school and at postgraduate level?

There have been very few clinicians or teachers outside of the psychotherapy sector willing to teach about this illness. Research is underfunded and the lack of research opportunities reduce the number of University Lecturers. Psychotherapists have a polarised view that the patient is wrong and they are

right, therefore patients have rarely been involved in the development of educational materials. Patients should be consulted much earlier in the development of educational materials. Doctors with ME are working with professionals and medical educators to get the patient and professional narrative updated with the scientific evidence. We need to train the trainers and introduce the new narrative via patient voices and a flipped classroom model.

Given the prevalence of ME do you see a time when medical schools will provide a compulsory module on ME?

It would be wonderful to develop some online learning for all medical schools to use. In the US there are some trials of ME being taught across 3 years in phases throughout medical school; this is the type of development which is really required. Perhaps modules made ready for academic year 2022-2023. Not soon enough for some patients I am sure, but please refer them to the healthcare professional updates on Doctors with ME: [Education | Doctors with M.E.](#)

What has shocked you the most regarding patient care and the gaps in medical knowledge?

A mind-boggling realisation is, before I had ME, reflecting on the way I felt seeing a patient with ME. I felt like I had been a good doctor, listening, being kind and holistic towards a ME patient. Later I learned, through my own experience of being a patient, that I didn't possibly have a clue as to how sick she really was, and how my ignorance must have been so obvious, and how the patient, by nodding and agreeing when I suggested she swim more, had protected me during the consultation. She probably had low expectations of the care that I could offer; patients with ME have learned not to expect a medical professional to understand. They have to fight for their care when they are some of the sickest patients and have the least energy. That's shocking. There are shocking cases of neglect, mainly all based around the false idea that the patient can make themselves get better. Other shocking examples are where a supportive family member has been put off believing their loved one who they have known and loved for years by a healthcare professional who, in a brief clinical encounter, attributes the disease and recovery to the thoughts, feelings and behaviour of patient and relative. The relative is so desperate for the patient to recover that they believe the healthcare professional over their loved one.

Is the money allocated to Long Covid going to benefit people with severe ME?

The biggest mistake would be to try versions of graded exercise and cognitive behavioural therapy on Long Covid patients, that would waste a few tens of millions. Money should drive the discovery of genetic links, treatments and a biomarker; if these are discovered for Long COVID then ME patients will benefit.

How would you suggest getting the maximum benefit from any medical appointment when you have severe ME?

Plan, rest beforehand, make a list, get a loved one to help you, family friend, charity member, someone who knows you. Ask someone trusted to stay with you, ask about the practical support you might need: accessibility, parking, transport, home visit, remote consultation over phone or video link, quiet dark room to lie down and wait, double appointment. Find a doctor who understands, or wants to learn. Ask for the information they give you to be explained slowly and in formats you need, large print, repeated again, ensure you have a follow up to take the pressure off everything being on one day. Send your doctor information or updates, they would be welcome to join Doctors with ME for support.

For a surgeon what are the additional risks for a patient with ME having surgery and are there extra precautions that should be taken, when operating?

Patients with ME can often have other diagnoses including connective tissue disorders e.g. Ehlers Danlos (EDS), mast cell activation syndrome (MCAS), orthostatic hypotension or Postural Tachycardia. Healing may take longer, scars may stretch more, some bruise more easily. There may be increased pain, increased C fibres, small fibre neuropathy and decreased tolerance to medications. If postoperative recovery requires staying overnight most ME patients would need a quiet side-room, accessible toilets, extra time to rest, gentle and patient specific mobilisation and stretching and ideally a patient information passport for hospital visits. Special diets and help with communication, medicine

sensitivities and other patient specific factors should be detailed, and hospital staff should be aware that the patient has limited energy and help them to conserve it. A goal for recovery for an ME patient is to save enough energy to heal from surgery; unlike other patients ME patients should not be encouraged to do more than they can.

We would like to thank Miss Nina Muirhead for taking time out of her schedule to answer these questions. Our next Q + A is with Caroline Kingdon from UK ME/CFS Biobank, London School of Hygiene and Tropical Medicine.