

What's in a name?

The power of power, narrative, and naming things that are so numerous we no longer see them.

Louise Kenward

In 2011 I got sick. For the years that followed I felt I must somehow be responsible. I felt blamed and ashamed. There was no clear line of thinking I could pinpoint at the time that would explain these feelings, it just was.

I returned to CAT in seeking further understanding and began to write about the experience of illness. Part of the felt awfulness, an additional burden of the illness itself, was in observing a community of unheard voices that had been sick before me and hearing of their reported interactions with doctors, society and the benefits system. Reciprocal Roles were being described; of dismissive, ignoring, disbelieving and undermining – patients were silenced and unheard, dismissed and disbelieved. As an observer, it felt like a hopeless position. Through my own experiences of being dismissed and unheard, with health care professionals and the benefits system, I came to see the power imbalance between Doctors and patients, and its implications, more acutely. I searched out the context of illness and disability in the wider community and in society. The sickness we experienced was felt so painfully because it was political.

To be sick, without a clear diagnosis or treatment has become particularly problematic. For those of us with energy limiting illnesses, invisible illnesses that often fluctuate, there is a greater degree of scepticism. It is hard to prove, and as such it is readily disputed. These are curious illnesses and conditions that render patients unable to do the simplest of task like wash or dress while outwardly there may be no sign that they would experience such difficulties. Many go undiagnosed for years as some

conditions are thought to be more rare than they are, and as such are rarely diagnosed (Demmler, 2019), while others have been caught in a new label of Medically Unexplained Physical Symptoms [MUPS] as a way to try to organise or make sense, but in practice seems to simply be an end to any further investigations, an updated term for 'hysteria' (Dusenbury, 2018). Many look similar to one another, with commonalities of debilitating fatigue and pain; many affect a disproportionate amount of women to men.

It is only in recent times that I have come to understand the bigger picture. *"It's not you, it's patriarchy"* – I've written down from listening to the final chapters of Rebecca Solnit's latest book *Recollections of my Non Existence* – it follows her own career in writing and the #MeToo movement. It has come at a time when I have found things crystallise, to increasingly recognise my own experience of the impact of the environment and societal structures, that led me to believing I was to blame, responsible for this illness, and the shame I have felt as a result. I have come to realise it has not been created from within but had been absorbed through the powerful reciprocity of roles set up in society. My earlier writing about my own experience of illness is what I now see as an attempt to give it shape and form beyond me, to show others, an attempt to defend myself perhaps – an attempt to say *"it's real"* and *"I didn't make this happen"*, hoping, perhaps that it would unlock the burden on me. That by speaking it and writing it I could release it.

Connecting the dots and internalising this has made me

reflect further, at a time where many more people are becoming ill and being left with limited energy levels. A proportion of patients recovering from CoVid-19 are being left with profound fatigue. One NHS Trust has tried to pre-empt this in publishing guidance on the psychological management of fatigue post CoVid-19. Unfortunately, it seems, they fell into several traps left in the shadows of previous research (PACE Trials) which has since been widely criticised. At the centre of what was potentially harmful advice was in equating post CoVid-19 fatigue with Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS).

Criticised by patient groups and allied professionals, this NHS booklet has now been withdrawn. It perpetuated the same damaging belief culture which led to my own sense of shame and blame in those early years of illness. In a letter signed by 24 professionals, patient groups and MPs, it stated that *"The information and advice... is inaccurate, misleading and contains potential harmful recommendations."* It details a particular concern of *"conflating post viral fatigue with myalgic encephalomyelitis (ME)"*. New appropriate guidance for post CoVid-19 rehabilitation *"to avoid exacerbation of symptoms and progression towards developing ME"* has been put together by Physios for ME and others as alternative guidance. At the heart of the withdrawn publication lies the key issues of ME/CFS treatment – that for so long, exercise (in the form of Graded Exercise Therapy) and Cognitive Behavioural Therapy (CBT) have been recommended interventions which lack a robustness of scientific evidence but continues to

inform NICE Guidance (postponed until 2021). The hypotheses for each treatment postulate that patients lose fitness due to a lack of exercise and resultant behavioural deconditioning, not because they are unable to exercise as a result of illness. Along with a false assumption that they remain ill due to beliefs that they are ill, not because they are, in fact ill, formed the core of the PACE Trials - a neat model that views the illness the responsibility of the patient. Whether or not the patient has caused it, they are certainly responsible for maintaining it, they are to blame. *It is all in your head.* This is not the first to have done so. Tuberculosis, cancer, asthma and multiple sclerosis among others have been considered psychological in basis until science and research discovered alternative explanations. In essence, once there are scientific ways of identifying and treating these conditions, in the form of biomarkers (unique indicators that can be reliably identified through blood tests, for example) and medications, they shift into something that can be seen and treated, or managed. While there are no clear biomarkers for ME, or effective treatments yet, it may continue to be viewed sceptically. This is a position that perpetuates a lack of funding, continuing to undermine patient accounts, sustaining a hierarchy and inequality, with the patient going unheard and the medical practitioner holding the knowledge and the voice. This, in turn, bears its own burden on doctors where there is not such a clear model on dealing with the unknown. To hold uncertainty can be a difficult task, and yet another, that as CAT therapists we are skilled at.

Myalgic Encephalomyelitis is a complex multi-system neurological condition, characterised by post-exertional malaise, neurocognitive dysfunction and unrefreshing

sleep. Secondary symptoms commonly include symptoms of the immune, neuro-endocrine, autonomic, and pain systems (Jason et al, 2015). The post-exertional malaise is of particular relevance here as many CoVid-19 patients are reporting profound fatigue on recovery. Advice to exercise “on good days and bad” (from the withdrawn publication) is considered potentially harmful, as it is believed that ME/CFS patients have developed (and worsened) their conditions due to attempts to ‘push through’ their own physical limitations, and not stop and rest as their body demands and needs. With NHS advice to do the same, patient groups and allied professionals are understandably concerned what the long term impact of CoVid-19 might be. ME/CFS patients often experience having had a virus prior to developing symptoms of this condition.

Research has continued beyond this previous UK contribution of recommending Graded Exercise Therapy and Cognitive Behavioural Therapy, which has delayed progress for many years. There are studies now into immunology and genetics among other disciplines, in understanding the illness and in search of treatment (Shepherd, 2020 & McGrath, 2019). Abnormalities have been shown in the central nervous system of patients, impacting on cognitive, autonomic and sensory functioning. Old systemic narratives are maintained however, by lack of knowledge and complexity of condition(s), undermining patient accounts as familiar frameworks are fallen back on, of considering illnesses we cannot see or treat effectively, as psychological in nature, further exacerbating the harm and damage caused and continuing to limit the progress that could be made with more open dialogues and discussions.

One piece of new research, driven entirely by patients living with chronic illness and energy impairment, was recently published by the Centre for Welfare Reform: Energy Impairment and Disability Inclusion – towards an advocacy movement for energy limiting chronic illness, in collaboration with the Disability Research on Independent Living and Learning. It follows a two year research project by Chronic Illness Inclusion Project and proposes the concept of energy impairment and energy limiting chronic illness (ELCI).

“Our research revealed a paradox: fatigue – or limited energy – is the most debilitating feature of many health conditions. But it is the feature that least entitles us to identify as a disabled person. We conclude that the very idea of ‘disability’ is socially constructed in a way that excludes us.”

This report goes on to mirror many of the experiences I have had in understanding and seeking help for my own condition. It feels like a way forward beyond the dialogue about Medically Unexplained Physical Symptoms [MUPS] and health structures that find these illnesses difficult to diagnose, and as such, hard to treat and manage. This can be frustrating for all involved.

“I think the biggest difference would just be being believed and feeling more deserving of respect in society, instead of feeling like I need to be constantly on the alert and constantly fighting my corner against people’s judgements and misinterpretations.” contributor to Energy Impairment and Disability Inclusion.

What I heard in those passages of Rebecca Solnit, as she speaks, of the #MeToo movement, and the many women abused by men, are the power in stories and of their need to be spoken and heard. So I see also the groups of patients who have equally been disenfranchised,

undermined and ignored as their stories were disputed, unheard and dismissed. In both situations resides the process of gaslighting – of an individual or group having their own word and experience disputed by another with power. Where inequality resides there is space for this to continue. As with sexism and gender inequality, this is gaslighting on a systemic level. Through reflection, writing and talking about these threads, I can more readily see these subtle yet powerful reciprocal roles at play. And so by developing this awareness – by noticing and naming – I am writing, in the hope that it can facilitate change, as I invite others to also notice and name, in calling a halt to discrimination. Within this dialogue of noticing and naming, there are new possibilities for change.

“We are all diminished by structures that create winners and losers instead of equals. Inequality is therefore one of the things that matter and one of the things we should mind about.” Brown, 2019.

Patients with ME have been subjected to public criticism and widespread contempt, with patients caricaturised as angry and suffering from *yuppie flu*. I have wondered at length why that might be – whether fear, of becoming *like them/us*, that such a debilitating illness with no cure or treatment might understandably be something to be feared, and as such these are attempts to make it *other*, to try to hold it at bay, or some other psychological construct that

limits the ability to hear the voices of those at the centre (who should be at the centre) of any enquiry.

In psychotherapy, the value of words and names is central, in developing a clarity of shared understanding, and in offering containment of unformulated experiences which are difficult, painful and unseen. The power of naming! It brings to mind a Grimm fairytale, Rumpelstiltskin: the story of an imp, who holds great imprisoning power over the miller's daughter. She is released only on the discovery of his name, and in speaking it out loud.

The power of a name and of speaking it out loud – with authority – subverts power. In naming, with noticing, so change will come, because of the moment of *naming*. As with Rumpelstiltskin, the miller's daughter did not do this alone, she recruited a helpful other, as we do in therapy. Collaborative working within a zone of proximal development, will enable us to help one another, as therapists and patients, in developing understanding and allowing these complex experiences to be heard – in turn enabling change and growth, for both

Rumpelstiltskin!
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Rumpelstiltskin!

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