

The Cheshire CAT: Reflections on 'Rabbit Holes'

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Thoughts that followed a talk for ACAT Physical Health Special Interest Group on 30th November 2018 a therapist living with chronic fatigue

I started writing, to find a way of making sense, to find a voice for what I was experiencing. In November, I presented at the Association of Cognitive and Analytic Therapy Physical Health Special Interest Group on my experiences of chronic fatigue and what I had learned from it, as a patient and as a psychologist and psychotherapist. This has long been a controversial illness, fluctuating in understanding by the medical profession as alternately physical and psychological – associated with trauma, with over achievers - and it makes me wonder just how many other illnesses are treated in this way. How many groups of patients are dissected for character flaws and personality traits? Mostly medicine focuses on the biochemical, the genetics and the metabolic. Mostly there is no judgement on who gets what diagnosis. But chronic fatigue, and related conditions, are not like other illness. After much consideration, research and conversation, the only explanation I can find to understand this is that where there is no conclusive scientific understanding, psychology is the fallback position. There's a track record for this: cancer was caused by a build-up of repressed anger and treated with group psychotherapy in the 1970s; the cause of multiple sclerosis was psychological until the MRI scanner was invented; asthma,

ulcers and tuberculosis were treated similarly. Psychologising these conditions and symptoms, because there is insufficient evidence for the alternative, is not good enough. It is not an open and collaborative dialogue in these understandings as it invalidates a crucial part in the dynamic, the patient.

When I first became ill in 2011 and received a diagnosis of Post Viral Fatigue, possibly triggered by the Epstein Barr virus (glandular fever), I began to investigate online. I did not stay curious for long. The anger and fear, the life stories of decades of illness and the fury of those reporting it was too much for my fragile state to cope with. I switched off my computer and distracted myself elsewhere until I was well enough to ignore it completely. Becoming ill again more recently, I have confronted this anew and explored further, beyond the anger and hostility to see what is behind it. Seven years after that first period of illness I now know that level of anger, I feel it powerfully and I try to find ways for it not to overwhelm and erode me.

The process of trying to make sense, of trying to recover, well enough, and of understanding what there is to understand, has helped me discover the richness of information held within the community of people with fatigue conditions. Weird things happening to bodies needing to be accepted, tolerated and coped with are par for the course for so many, often dealt with dignity and matter of fact attitudes. People with lifetimes of experience in how their bodies do and don't work, of negotiating unhelpful and abusive

health professionals whom they turn to for answers are rich resources of knowledge and wisdom. Over time it seems a disparity has developed and grown, unscientific research and invalidated trials such as PACE have deepened gaps between patient and professional, where mistrust has fostered on both sides. The cavern has widened to such a degree that it has become a different language entirely. In a place where the use of words is so important, for all its nuances, language is powerful.

It is for all of these reasons that I turned to CAT - a model that has navigated me through so many case formulations in team meetings, individual therapies for a range of people with a variety of diagnoses, and a multitude of supervision sessions. At its core is collaboration, of sharing a language, led by the patient, and checking understanding through letters, diagrams and dialogue.

Early last year I started an application for PIP, the current disability support benefit. I was reluctant and managed for as long as I could without, wiping out savings and moving house. The forms are daunting and impossible to complete independently, this does nothing to remind me of the functioning and capable adult I had been, negotiating risk assessments and complex case formulations as a team psychologist. Perhaps I was no longer that person? I was reduced to bodily functions in these forms, what I could and couldn't do – can you use the bathroom independently? Dress yourself? Go out alone? Questions

that bore no relation to the things I was struggling most with, but were also challenges, I couldn't always wash or dress or get up. The process left me feeling utterly humiliated. It struck me – how much of the forms, assessments and processes had I been party to for patients that had the same effect on them? I was being asked to describe myself in a way that I could not recognise as me. The core of me was lost. I thought about care plans and working within a strengths model – this focused on the positive, surely a good thing? Yet, again, at its core, was the illness, centre-stage. The reason for the contact was illness, the identity in that context was as a person with an illness. Focusing, dwelling on being ill and concentrating on it can make this feel much more a part of me, much more my identity than I think it is, than I think it should. I repel this and it makes me wonder more about the people I have worked with, whom I have assessed and made decisions about.

During my talk in London last year I was struck by several things. Firstly, that despite feeling like a bit of a guinea pig when first asked to present, I had overcome my own concerns about how I may be regarded, but was struck by how rarely people with illnesses have this kind of platform, how little we (as health professionals) actively seek out input from patients in anything more than a service user feedback or the occasional open day. Secondly, one of the participants working with people with a diagnosis of fibromyalgia, shared that she had noticed that much of her work is spent unpicking the work of other health professionals, undoing detrimental things said and attitudes held. And thirdly, a conversation I was at the edge of during lunch, just as I arrived, was about whether, in knowing someone has a diagnosis, such as autism, should they be told?

At this point my ear wiggling could not be ignored any longer and, having

followed and spoken to Katherine May (2018), who has written beautifully and powerfully about her own diagnosis of autism later in life, found it freeing, making sense of all the things she had found difficult, and led to her responding to situations and information differently to others around her, throughout her life. I shared this, impressed at the burgeoning literature that is addressing powerful issues with (I believe) direct clinical implications for practitioners. Claire Best (2017) has written, also powerfully and beautifully about her own experience of making a decision to have a double mastectomy in response to her family history of breast cancer. This work, *Breastless*, led to a series of presentations at medical training events and an image (her image), being made available to other women contemplating mastectomy, of what the body would look like without reconstructive surgery – for the first time. These are capable, intelligent, thoughtful works, with a great deal to offer, creatively and therapeutically. I hope that there are similar possibilities through literature and art in exploring and impacting on the experience and treatment of fatigue conditions.

I worry for the disconnect between patients and professionals, and am concerned that this is just my worry, that I did not pay enough attention, that I was secure in the knowledge I was the professional, and that this held some protection from being the patient, an arrogance of knowing. It is our humanity that unites us and I can't help but wonder how much more there is to be learned from patients. This feels like an age-old plea for more service user engagement but at its heart this is fundamental.

As professionals, we need to lose any sense that we know better about the cause for these illnesses, or their impact, where it remains scientifically unclear. There is much that can be offered in therapy without judgement,

explanation or expectation. The process of being ill, for a long time, is enough to deal with – work on grief, loss and acceptance to new levels of ability is all valuable work that is not routinely offered. Where there are no cures, acceptance of this may be as difficult for the therapist as the patient. Learning how to cope and being understood, while science catches up, may be the best we can hope for – certainly it is good enough.

In the meantime there may well be surprising outcomes. For me, prolonged periods of rest and solitude has led me to assess my life and the decisions I make about it very differently. I have gained something as well as losing a great deal, although the two are not equal. Unable to return to work in the period Human Resources required me to meant that I could recover at my own rate, while travelling abroad and living on the rental income from my flat. This latest period of illness has led me here, to writing and talking, and making art, to understand and make sense of what this strange thing I live with is. It has led me to pursuing further creative projects. Using my CAT tools more creatively has contributed to me finding a new voice, of developing a new language, in writing to my illness. These are things I would never have done if I had not become ill in the first place. These are not silver linings and I am far from grateful for my illness, but we have reached a kind of bargaining space, I am able to navigate the gaps.

It has made me wonder about my practice, what I was like as a psychologist - with the people I worked with as a psychotherapist and the teams I spent time with, developing formulations and understanding. It has made me cautious of psychology and therapy – as there has been such a hostile ambush to/of the discipline in this field of illness. Psychologising physical illnesses, a pattern it seems with anything that we do not fully

understand, for which there is no clear scientific explanation. Especially, perhaps, when it is largely a female population who experience these curious illnesses. It has made me wonder about the kinds of terminology used in illness, the kinds of phrases heard – ‘heart sink’ and ‘medically unexplained symptoms’ for example – words that mean nothing in terms of clinical practice as far as I can see, other than to stigmatise and make judgement on the person with these symptoms and experiences – distancing them even further. It has made me think really carefully about the difference between mental and physical health, when it is increasingly clear that we are all of one whole body, and when just as it seems we are adjusting societies attitudes to mental health for the better, that to be told a physical symptom is ‘in your

head’ remains the most brutal and dismissive response that can be made.

It has made me think about the value of psychotherapy in adjusting to, and coming to terms with, a life altering condition, for which there is enormous stigma and with an inverse proportion of understanding and treatment. It has made me realise that psychotherapy can help make life a little easier, in the same way it does for people who do not have such energy limiting illnesses. It does not mean that the illness is psychological or will be ‘cured’ with therapy, but it does mean that – resources permitted (emotional, physical and financial) – becoming a more aware, more grounded and accepting person, of yourself

and others, can help to reduce some of the things that otherwise make life even harder, more stressful and upsetting. Just as they would for a person without a physical health condition.

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