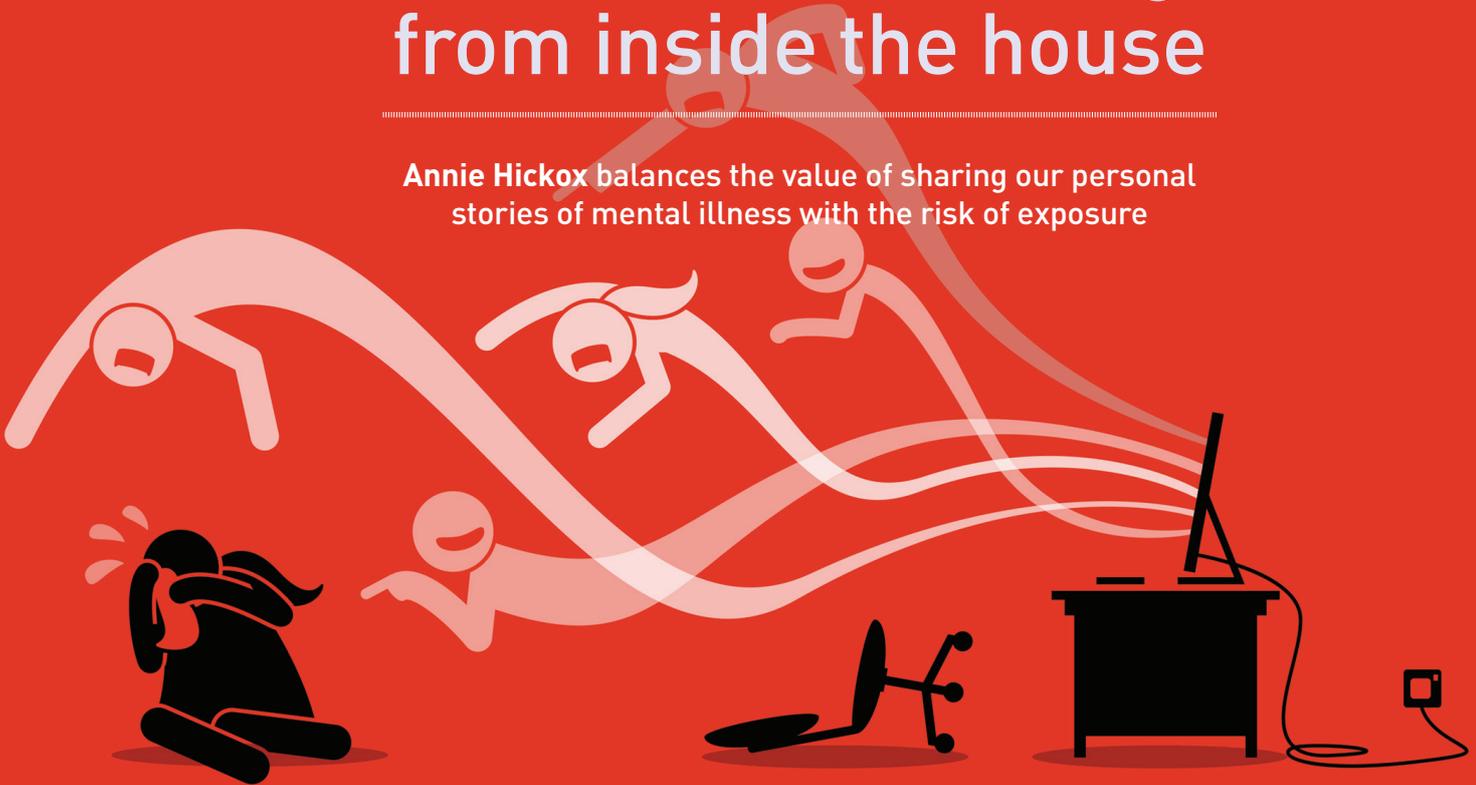


The threat is coming from inside the house

Annie Hickox balances the value of sharing our personal stories of mental illness with the risk of exposure



It was never my intention to write about my lived experience of mental illness. In 2019, I wrote an article about my daughter's depression and my experience of this both as a mother and as a clinical psychologist. It took me two years to finish, I broke down in tears a few times while writing it, and at one point I was ready to abandon the project altogether. I asked myself if the pain of reviving memories of this difficult time outweighed the potential value of what I was writing. But my daughter Jane, who has suffered from severe depression, wouldn't let me off the hook. We agreed that if the piece helped even a single reader to feel less alone, it would be worth the effort and uncertainty. With that potential reader in my mind, I pushed myself to finish those last few sentences.

My account was about my efforts to walk the tightrope of being both a mental health professional and a mother; a line I wobbled off several times, and still do. I wanted readers to know that, despite the shame and sense of failure that I felt in myself and the imposter syndrome I experienced in my workplace,

it was still worth talking about my own fallibility openly, while not exposing too much about my daughter's personal suffering.

My article was published on *The Psychologist* website, shared on Twitter and in due course appeared in the print magazine too. While I had expected a few people to read my brief memoir, I was overwhelmed by a stream of public and private messages. These came from mental health and medical professionals, patients, and parents who shared with me their past and current struggles at home with their own young adult children suffering from depression, anxiety, and OCD. Reading each one of these poignant confidences, which tended to start with 'Thank you for telling your story, now here is my story...' filled me with a profound sense of humility and empathy for the people who entrusted me with their own raw experiences.

Sharing my story for the first time on social media felt like I was taking a huge risk in the fragile hope that adding my voice as a professional would encourage others to do so. I have the good fortune to be part of a vast and varied mental health twitter community, sometimes known as #madtwitter, #mentaltwitter or

#mentalhealthtwitter. This is an extremely diverse and broad group of mental health professionals, patients, and others with lived experience of mental illness. I have always admired people who told their own stories about their own illness trajectories and how they navigated the labyrinth of NHS services that are far too often bewildering, opaque, and infuriatingly inadequate.

I also heard from many fellow mental health professionals who related their own lived experiences, and the strong sense of shame they suffered when they spoke openly to colleagues about their mental health struggles. Although we are a profession whose work often entails encouraging others to open up and share their trauma and personal pain, it seems we are also a profession who finds it far more difficult to listen to each other recount our own stories.

Woven into family life

Clinical psychology is based on the scientist-practitioner model, and recognises that informed choice and evidence-based knowledge can help people find the best path to deal with their mental health issues. On social media, most of us see our role primarily as providers of information engaging with allied mental health professionals and service users. I have therefore always steered away from discussing my own family history of intergenerational mental illness, limiting myself to the occasional comment about the impact of my father's severe mental illness on my early childhood and adolescence.

Every family that experiences severe mental illness knows how it can sweep in like a tempest, pulling everyone into its force. I grew up in the 1960s, during a time that saw the first generation of modern psychotropic medications. Their unpredictable interactions, the care with which they were prescribed, and the question of who should be doing the prescribing, were frequently overlooked. The clash of diverse and often incompatible medications frequently exacerbated our father's condition in unpredictable and alarming ways.

The complex triangular relationship between my father's haunting memories of his childhood trauma, his depression and his psychosis still runs through my mind every day. They left an indelible mark imprinted on every recollection of our childhood and the rhythm of our family life. During his periods of being well, the glimpses of increasing stability and joy during Dad's days of gradual recovery felt like sea spray from a surf that still held the power to pull him under again. Sometimes as a child I would visit friends and be mystified by those families for whom these psychological forces appeared to be absent. I would wonder, 'what can that be like?'

Decades later, my four siblings and I always return, again and again, to discussions and debriefings about our father's illness and the imprint that it left on each of us. These recursive reminiscences (and even at times

laughing darkly when we recall a particularly vivid episode that would have seemed absurdly comical if it had been portrayed on a television series) continue to provide us with the paradox of the combined pain and balm of shared experience. We knew we were not alone and we are not alone. Mental illness in the family has provided us with a shared language and ease in handling the subject that is, perhaps, unusual.

I feel grateful that I have always felt able to talk openly and unashamedly to my husband and my children about our family history. My therapeutic work has led me to admire my father even more, the fact that after all of his suffering, and several suicide attempts, he still managed somehow to survive for our mother and for us. He had no means of hiding his vulnerability, and even with our mother's best efforts to keep the show on the road, there was no way to shelter us from these episodes. This has perhaps been one of the greatest lessons of growing up with a mentally disordered father. Mental illness has always been intricately woven into my family's life, even for generations before I was born, and it continues to this very day.

Shame and stigma from inside the profession

So talking about mental illness in the family can be a healing, bonding, and educational experience... until it isn't.

Things can and do go wrong when we expose our vulnerability and anguish to people outside of our close personal circle, especially on social media. The initially overwhelming Twitter response to my article reminded me of William Styron's observation of his own depression: 'the disease engenders lasting fellowship, if nothing else'. And yet, my attention was drawn to a handful of tweets that felt stigmatising and shaming, suggesting that I had 'medicated' my daughter, that I myself was 'probably mentally ill' and 'unfit to work as a mental health professional', and 'probably on drugs herself'.

The momentary sting of these few speculative tweets did not last. I knew that they had been written by people who had described deeply distressing experiences with mental health services, and I reflected that my own memoir may have stirred up resentments and anger. As a highly privileged clinical psychologist, I was a ready target.

The stigma was more striking, though, when messages on social media came from a couple of members of my own profession. A clinical psychologist described my article as evidence that I was 'dragging' my daughter and family into an apparently self-serving drive to support diagnosis and psychiatry. A psychotherapist chastised me for taking my daughter to her GP, saying, 'what a shame you went straight to a bio bio bio treatment without considering addressing the root causes', even though I had written at length in the piece about the profound value that therapy gives to Jane.

When I read these social media messages, I was reminded of the urban legend horror trope, 'the calls are coming from inside the house'... the creepy phone calls that come from the last place one would expect, the safety of one's own domain. In this case, the threat was in fact written without the shield of anonymity, by members of the British Psychological Society.

I asked myself why the social media comments felt so shaming, when in my day to day life I feel so at ease in discussing my personal experience of mental illness with friends and family. I also thought about why, in contrast, I have always tended to freeze at the thought of talking about it at work, or writing about it publicly. It had always seemed that by keeping my stories hidden, I could avoid the struggle of deciding between what to reveal and what to withhold from the light, to protect.

My own small experience of social media shaming is, of course, personal and anecdotal, but my reaction caused me to consider how we as a profession deal with disclosure of our mental health histories to our fellow professionals. I reflected on the many psychologists who, like me, had lived experience and would also see these brief messages as a warning shot that said, 'Hush. If you try to tell your story we will distort it and use it against you'.

Clinical psychologists with lived experience

Was I being overly sensitive? I decided to find out a bit more about the prevalence of mental illness in our profession, and whether the sense of being shamed by members of our own profession was common. I discovered that I am in good company. I knew that many studies have shown that a majority of mental health professionals have personally experienced diagnosable mental illness, and that the statistics appear to be consistent across these various reports. But a particularly relevant study is a 2018 paper by Stacie Tay and colleagues in the *Journal of Clinical Psychology*, surveying members of the British Psychological Society's Division of Clinical Psychology (DCP); in other words, my own profession.

Their research indicates that over 62 per cent of us have lived experience of diagnosable mental health problems, with depression and anxiety most commonly experienced. Clinical Psychologists experience high levels of stigma, and while we appear to be comfortable disclosing our experience to our family and friends (68.2 per cent) far fewer of us felt able to disclose to work settings (44.5 per cent). The most negative experience of disclosure was with employers.

The survey also showed that those of us who have lived experience sought help either from our GPs or from private psychiatrists. Therefore, while the majority of us experience mental health problems, most of us are reluctant to disclose how we feel to our work colleagues. The barriers for seeking help at work include perceived mental health stigma, shame, and negative consequences of disclosure particularly towards our careers. (As an aside, I remember receiving this survey, as a member of the DCP, and briefly hesitating to complete it for fear that somehow my replies would be shared with my employers).

Overall, it appears that our profession has a long way to go before those of us with lived experience of mental illness can feel safe in talking openly with our colleagues about our struggles. And yet, promoting openness about lived experience in the workplace

would seem essential in allowing us to feel that it is really okay to speak candidly and without fear about our mental health, and to ask for support when needed.

We may, no doubt, encounter many barriers in reaching this goal, but two strike me as particularly salient. The first is the emphasis on resilience in the workplace, which conflicts with the message that we should open up and reveal our vulnerability. In the NHS, resilience

training is often seen as a way of helping workers 'bounce back' and is often equated with success, productivity, and leadership.

A second barrier is the view of some psychologists who appear to normalise mental illness and refute the widely accepted position that diagnosis and medication can have significant therapeutic value. Advocates of 'critical psychology' consider diagnostic constructs to be invalid and also consider the term 'mental illness' to reflect a failed and outdated psychiatric paradigm. Abridging and modifying the language we use, it is argued, will lead to an elision of these traditional concepts.

In the 2020 BPS Division of Clinical Psychology document, *Understanding Depression*, the term 'illness' is eschewed by the authors, who prefer to describe depression in 'its everyday sense' as something we experience 'just as we experience anxiety, anger, or even love or joy'. The authors state that 'we don't necessarily need 'treatment''. They advocate for practical support and help to make changes, favourably listing non-clinical interventions such as yoga, mindfulness, and 'healthy environments'. As Ronald W. Pies states in his *Psychiatric Times* article, 'Is Depression a Disease?', 'the BPS report barely discusses the benefits of antidepressant treatment, including improved quality of life, but spills a great deal of ink discussing its potential risks and side effects'. The misalignment between the two perspectives of normalisation and illness has also jarred with

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non-professionals. Lucy Dimbylow, a suicide survivor with an extensive history of severe mental illness, states in her blog that “common human experiences” have no relation whatsoever to the severe, enduring clinical depression that leaves me bleeding on the bathroom floor or semi-conscious in the back of an ambulance...’ And in her *Morning Star* article ‘Semantics instead of treatment’, the journalist Ruth F. Hunt quotes a psychologist who states succinctly, ‘depression (or sadness) as a mood state – such as grief, will come and go. Depression as a clinical disorder does not go away’.

Feeling our experiences are minimised or ignored is yet another barrier between us and our colleagues. Hunt, who has suffered from disabling depression and physical disability since her teens, has written that in the ‘move away from an ‘illness’ to ‘personal responsibility’... the onus is on the patient to find the answers so they can get themselves better. For service-users this undermines and invalidates their lived experience of devastating prolonged bouts of illness’. For the many members of our profession who have experienced the crippling effects of mental health conditions, the current emphasis on resilience and/or normalisation of what for many is a paralysing illness can sound like ‘pull yourself up by your bootstraps’.

Signs of change

Would eradicating diagnosis really reduce stigma and shame about our mental health experiences? The accounts of clinical psychologists experiencing shame in the workplace tell a different story.

In a poignant and candid letter to *The Psychologist* (November 2020), Khadija Rouf describes the ‘real, and as yet, unnamed form of prejudice and discrimination against people who are survivors’. It was Rouf’s experience of being helped by social workers and psychologists that sparked her desire to eventually train as a clinical psychologist, yet she suffered ‘an unhealthy and invasive level of scrutiny during training and ‘assumptions made about my past... silencing and shaming’. Colleagues questioned her professional judgement due to her survivor status, yet ‘they never appeared to question whether they knew enough about victim and survivor experiences’.

Rouf’s experience will resonate with the majority of our profession who have lived experience of mental illness. ‘It’s a strange kind of binary, where a profession built on understanding the human psyche, cannot cope with a person who happens to be both a survivor and a clinician’. It appears that it is not the diagnosis that is shaming, but the attitudes we face when we cross the liminal boundary between hiding and disclosing our mental health difficulties.



Dr Annie Hickox, CPsychol, PhD is a clinical neuropsychologist with over 35 years of clinical experience in the NHS and private practice. Find her on Twitter @dranniehickox

Rouf’s words stand out in their own right, but are particularly salient in view of the BPS/DCP document, ‘Statement on clinical psychologists with lived experience of mental health difficulties’, published in August 2020. Like Rouf, I welcomed this development, although I felt it was long overdue. This document states clearly that the DCP publicly

recognises and supports the ‘unique and valued contribution that lived experience of mental health difficulties brings to individuals working within clinical psychology’. It also acknowledges the stark conflict that arises regarding whether we share our experiences in the workplace. ‘Significant change is needed before individuals are able to feel confident in receiving normalising, compassionate and accepting responses, as opposed to those that are dismissive, denying, attacking, ‘othering’ or marginalising’. The authors state the need for a ‘whole-systems responsibility’ at all levels of the profession.

The DCP’s statement is laudatory, and I applaud courageous clinicians such as Khadija Rouf, Anna Chiara Sicilia, Natalie Kemp, and others who have underlined the powerful potential that the meaning and resonance of this document may have.

Telling who we really are

We need to be able to talk about our experience and know that the risk of disclosure does not outweigh the benefits of sharing our stories, which are, after all, such an important part of our identity. Lived experience of mental illness in our profession is common; the majority of us have lived experience of diagnosable mental health conditions. In my own case, I grew up with a parent who suffered psychotic depression and mental illness was tightly woven into my childhood. I suffered psychosis during my teen years, and both of my children suffer from anxiety and depression. I do not see it as an asset nor as a drawback, it is simply who I am, and it is who we are. It is indelible, and denying it or minimising it will not erase it. We all need to speak up and to speak out.

We need to share our stories and have them heard and validated by all levels of our profession. Lived experience can be an asset in our work. But our profession’s discomfort, expressed by shaming and silence, is a fault that runs deep, whether in the workplace or on social media. If we work together to remove mental health shaming from our profession, we can begin to tell people who we really are, rather than let them tell us who we are not.