Seen and held: creating containers for healing

Reflections from chronic illness and recovery

Louise McAllan

Recovery practitioner

I spent eight years of my thirties mostly bedbound with chronic illness, and it was through losing and then rebuilding a life that I came to understand healing as more than the fixing of symptoms. Recovery led me to retrain as the guide I had needed. I am a recovery practitioner trained in emotional awareness and expression therapy (EAET), with a particular interest in the emotional drivers of persistent symptoms, especially fatigue and functional neurological disorder. My work centres on relational, evidence-based approaches for people often described as complex, particularly through therapeutic group work and retreats. I have co-led an EAET pilot in Edinburgh; I also mentor healthcare professionals and speak and write about recovery, emotional health and the human dimensions of healing and healthcare.

Summary

McAllan recounts eight years of medically unexplained, disabling symptoms (ME/CFS, FND, PoTS) following collapse in her 30s, and her recovery through understanding symptoms as protective nervous-system responses rather than damage. Now a recovery practitioner in emotional awareness and expression therapy (EAET), she argues persistent symptoms often reflect suppressed emotion and relational wounding, and that healing requires safety, validation and peer connection rather than fixing. Group work, evidenced by rising patient-activation scores in an Edinburgh EAET pilot, offers a relational container where lived experience and shared understanding do therapeutic work individual treatment cannot.

Summary

When symptoms have no structural explanation, the patient's trajectory through healthcare is often very different from the one they expected. There is no broken bone to set, no tumour to remove, no clear pathway out. Instead, many of us find ourselves in new and unknown territory, trying to navigate a strange land with no map, and encountering paradigms of health and illness we never knew existed. Along the way, the journey itself is often traumatising, carrying with it loss, fear and the gradual breakdown of trust in the system that is trying to help us.

My own experience, first as a patient and now as a practitioner, has taught me that for many people with persistent symptoms, fixing and being fixed have to make way for something more holistic. What is needed is validation, community, peer support and containment: spaces where healing can unfold over time rather than be delivered as a quick repair. This article is about what those containers might look like, why groups can be so powerful and how we might measure success when improvement is a journey rather than a cure.

My journey into the unknown

Shortly after my 30th birthday, I collapsed at work while working as a primary school teacher. At the time it seemed to come out of the blue, but looking back I had spent more than a year visiting my doctor with strange and unexplained symptoms. Every test came back clear, yet I had an internal tremor, unexplained pain, difficulty standing without feeling faint and had been spending evenings and

weekends wiped out in bed. Each morning I rallied myself, pushing through to get to work and make it through the day.

On the day of my collapse I was rushed to hospital with stroke-like symptoms and seizures, feeling trapped inside a body over which I had absolutely no control. After several weeks of extensive testing, they found no structural cause and I was told that my symptoms were functional: a problem with the software of the brain rather than the hardware of the body. At first I was hopeful there would be a solution. Instead, it marked the beginning of an eight-year journey through persistent symptoms that turned my life upside down.

> Having symptoms which affected me profoundly but were largely self-reported brought a level of stigma

My experience of healthcare until that point had taught me that when something went wrong in my body, I went to the doctor and they fixed it. I hadn't realised how much security that belief gave me until it collapsed. Losing it was deeply destabilising, and it set me on a relentless search for an answer that made more sense to me. I became convinced something had been missed and entered what I often call my safari through the medical system: bouncing between specialists, investigations, diagnoses and possible treatments. Over the next eight years I was diagnosed with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural tachycardia syndrome (PoTS), functional neurological disorder (FND), fibromyalgia, chronic vestibular migraine and more. I was medically retired from the teaching job I loved and became mostly confined to my bed. I lost the identities through which I had understood myself: daughter, sister, teacher, friend and all the things that had brought purpose to my life.

Having symptoms which affected me profoundly but were largely self-reported brought a level of stigma I had not experienced before. I began entering appointments already expecting not to be believed. As each specialist ran out of solutions, my appointments became less frequent and I was discharged back into the care of my GP. I became disconnected from the medical system, which I experienced as having abandoned me, and disconnected from my own body, which seemed to have turned against me. Eventually I stopped searching altogether and sank into a deep acceptance of my situation, carefully managing my activities and giving up any hope of recovery.

In this way, persistent illness can not only be influenced by trauma but also be a source of it. A system designed to investigate and treat us can inadvertently add to our distress when no clear answer or pathway is available. Many patients eventually turn away from healthcare and travel instead into the online wilderness, where they may hear that recovery is impossible, or find an endless succession of private treatments and miracle cures which cost them both money and hope.

Key factors in recovery

Progress became possible when I was introduced to a radically different way of understanding my symptoms. For the first time, I was invited to consider that my body was not broken or betraying me, but acting in my own best interests. My nervous system had become stuck in a protective response and my serious and disabling symptoms were an expression of protection rather than damage. That single shift changed how I related to my body. Instead of responding to symptoms by fighting, rejecting or constantly monitoring them, I learned how to turn towards sensations in a way that communicated safety rather than alarm. Through this new understanding of how my body works and this new way of relating to my symptoms, I saw improvement for the first time in years.

But symptom improvement was only the beginning. As my body settled, I began to understand what had led it into such a profound state of protection. Rejection sensitivity had shaped patterns of pleasing, masking and avoidance. I had learned to suppress the natural movement of my emotions until I felt numb and disconnected. I was living inside a damaging marriage, pushing myself to succeed in a stressful career and repeatedly abandoning my own needs to maintain connection with others. My symptoms were not simply the problem. They were an intelligent response to the distress and imbalance in my life.

Recovery, for me, rested on three interwoven strands: learning to feel safe in my body; bringing emotions back online and learning to express what had been suppressed; and understanding the life factors that needed to change. Medical interventions remain valuable or essential, but there is no pill that can identify where someone feels lonely and unloved. No surgical procedure can help a person discover where a boundary is needed, find the voice with which to express it or feel safe enough to experience anger that has been held down for years. This part of healing asks something different of us. It is an active, immersive process that requires time, guidance, support and connection on a very human level with those who have walked the path. For me, this was my friend Fiona, who introduced me to the mind-body approach and became an invaluable friend and guide as we navigated our inner worlds and relearned how to exist and function in the outer one.

Group work as a container for healing

That friendship gave me my first real understanding of the importance of fellow travellers. Just as I had felt that only someone who had lived through severe illness could truly

understand it, recovery also felt like a strange and singular experience that could only be understood by someone who had been there. I see this echoed in my work now: the importance of lived experience, peer support and feeling deeply seen, both by those travelling alongside you and by those who can help guide the way.

Trauma is often relational. It develops through what happens, or does not happen, between people: where we are frightened, controlled, rejected, unseen or left alone with experiences we cannot hold. It follows that much of the repair must also be relational, and this is why so much of my work now happens in groups.

I begin my groups by making space for people to talk about what they have already lived through, including the trauma acquired while navigating healthcare. It is an invitation to bring the baggage they have been carrying and place it down. Participants are often surprised by this. In previous settings, some have been encouraged only to be positive and focus on moving forwards. My experience has taught me that before many people can move forwards, they need permission to feel and express what has come before and to have it witnessed.

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A group of people who understand can provide the relational container for this in a way that individual education or self-directed tools cannot. Seeing your own experience reflected through others is profoundly validating. People arrive believing they are the only one. Then they discover that their fears, shame, patterns and experiences are deeply human. There is a move away from the isolation that so often characterises both illness and treatment, while still holding space for each person's unique circumstances; the shared framework is the same, though every story within it is different.

My own online group programme is built on evidence-based approaches: mindfulness, pain reprocessing therapy (PRT) and emotional awareness and expression therapy (EAET). The programme has run for several years now, and in my experience the group setting can be powerful, sometimes even more powerful than one-to-one work for the right people. Within the container of the group, participants learn to relate to their bodies in a new way, to process and express emotion that has been suppressed for years, and to retrain the learned neural pathways and predictive patterns of the brain that can cause symptoms to persist. They are not passive recipients of treatment, but active partners in understanding what has happened and discovering what they need. And while my own recovery brought me to this work, what I offer does not come from simply teaching people what happened to me. It comes from my training and from years of practice alongside people who arrive carrying labels like 'complex' and 'difficult', and who have taught me more than any course could.

Even mindfulness, PRT and EAET can be reduced to modalities and frameworks, another prescription of tools and protocols, if we lose sight of the bigger picture. And yet, as valuable as these approaches are, the most profound changes I witness are rarely about technique. They happen when someone feels truly seen and understood for the first time, when they no longer have to prove their symptoms and can start rebuilding a life that is theirs: seen and held. This involves a paradigm shift for everyone, practitioner and patient alike.

Is this impossible in our current system?

I must admit that I am, by nature, an optimist. But I do not believe that relational, evidence-based containers for healing are a fantasy; they have the potential to have a big impact on both improving patient outcomes and easing pressure on the system. PRT has produced substantial and durable improvements for people with primary chronic back pain (Ashar *et al*, 2022), and EAET has demonstrated benefits across chronic pain populations (Lumley *et al*, 2017), including, in a 2024 trial involving older veterans with medically and psychiatrically complex pain, greater reductions in pain than cognitive behavioural therapy (Yarns *et al*, 2024). No one model will suit everyone, but these findings show that working directly with fear, emotional conflict, trauma and protective brain processes deserves a meaningful place within pain care.

This was my experience here in Scotland when I recently trialled EAET in a community setting with Dr Barbara Phipps and Ed Giles. The project was undertaken through Health All Round, an Edinburgh-based charity, and built on Barbara and Ed's well-established and successful community-based group model, Action for Pain. The most striking changes we saw in participants echoed the changes I see in my own groups: participants became more knowledgeable, skilled and confident in managing their health, less frightened of their bodies, and more connected to their relationships and lives.

Measuring success

If we are stepping outside of the fixing model, success in these programmes ought not to be defined only by whether every symptom disappears. Alongside changes in symptoms, function and quality of life, we can measure patient activation: the extent to which someone feels able to understand and participate in their own healthcare, captured through the validated patient activation measure (Hibbard *et al*, 2004). In our Edinburgh pilot, early findings show patient activation rising by an average of 9 points per person. Higher activation is consistently associated with better health outcomes and better experiences of care

(Hibbard & Greene, 2013), and with lower use of GP, emergency and inpatient services (Barker *et al*, 2018). This matters for two reasons. First, it offers a meaningful marker of progress in a situation where recovery is a journey rather than a quick fix. Second, the same shift that helps people manage their health also tends to reduce demand on an already overstretched system. So what is good for patients turns out to be good for the system too.

Conclusion

None of this is a replacement for investigation, diagnosis, medication, rehabilitation or appropriate medical intervention. These containers must sit alongside medical care, with clear screening, appropriate safeguards and honest acknowledgement of the limits of any particular model. What they offer is a much-needed treatment pathway for people who are currently lost in the system, with nowhere else to go. For me, the fear and lack of control that came with running out of medical options was one of the most distressing parts of being ill. A framework for understanding and improving my symptoms would have been like someone throwing me a rope.

When I was ill, I wanted someone to fix me. When I became a practitioner, I wanted to fix others. Both came from the same deeply human place: wanting suffering to stop. But healing required more than a fix. Before anything else, it needed the trauma I had acquired within the medical system itself to be acknowledged and witnessed. This was healing in itself. It required good science and clear information, alongside validation, relationship, emotional expression, support and time. It required somewhere I could feel safe enough to be seen.

Perhaps trauma-informed healthcare does not begin with another intervention. Perhaps it begins by recognising that we are not 'doing healing' to our patients but meeting them as partners in an active and deeply human process.

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