Reflecting on Reflections: A Conceptual Revisit to "Learning and Long-Term Illness"

Susan Sapsed, Independent Scholar, UK
'
Dr. David Mathew, Learning & Development Manager, NHS
Arden & GEM CSU, UK

Rev. Andrew Fielding, Hospital Chaplain (Retired), UK

Abstract

Why does one write about one's experiences? What is the purpose and function of committing our thoughts to a diary that will have no guaranteed readership (in the normal course of events)? This paper tells the story of the lead author's discovery of a diary that she had penned four decades earlier (beginning in 1982), which covered (*inter alia*) her experience of being diagnosed with Ménière'sSyndrome, a disorder of the inner ear that often leads to dizzy spells and hearing loss for the one afflicted. This diary could have been left alone, but sensing something valuable in the message the book contained, the lead author arranged for her handwritten notes to be typed up by a colleague, and after much deliberation, using extracts from the diary, the second author wove it into a book, thereby introducing and using his concept of Saturated Spaces.

Learning and Long-Term Illness: Saturated Spaces was published in 2022 (Mathew & Sapsed, 2022), as a reflection on generations of healthcare from the point of view of a midwife, scholar and reflective thinker – someone inside the system as a patient, but also a commentator on that same system. This paper picks up that story and discusses what has happened since. Given the intention of this work, it should come as no surprise that entries have been made from a post-book-publication standpoint, in the first person. The authors have decided not to reprint work from the book itself; instead, they refer the reader to it, for a richer background and for its own story to tell.

Background to the "Learning and Long-Term Illness" Book Project

Between 1982 and 1993, Susan Sapsed kept a diary that is referred to throughout the book that eventually became *Learning and Long-Term Illness*. She began this diary when she was 37 years of age, convinced that she was suffering from Ménière'sSyndrome (a disorder of the inner ear that often leads to dizzy spells and hearing loss for the one afflicted). Nearly 40 years later, while preparing for her retirement from the University of Bedfordshire, Susan discovered the diary by chance. It told a story of personal illness, practitioner misunderstanding, patient frustration and familial loss. It was clear to the authors of the book that it could be used as a starting point for a meditation on patient power and powerlessness, and as an analytic comparison between healthcare systems at play in the past and in the present.

Using psychoanalytic frameworks, the book invited a more mature Susan to reflect on her earlier self and on treatment that was not always worthy of the name. It explored ideas of agency and what purpose a diary really serves. Although the diary was not presented in its entirety, some unedited passages wereincluded. The book explored the earlier contributions, presenting a narrative that combined the old and the new.Continuing in the spirit of the book, we now present Susan's thoughts as of the current time. She writes in 2024:

"Why I kept my diary in those days I am not quite sure – possibly as a reminder that during my career as a Midwife and Nurse you needed to listen to the women, as I felt I was not listened to during those years. A kind colleague made me laugh and said nobody would ever get through my diary unless it was typed up, and he gamely took it on."

From this contribution to the story, we can infer, quite easily, that Susan had intended, on some level at least, for her diary to be read. We might agree that this expectation is out of the ordinary. What one commits to the diary is usually first draft, possibly clumsy, immediate, and above all, *personal*: these gobbets are *my* gobbets, not intended for a wider readership. These joys are *my* joys; these pains are *my* pains. The same goes for successes and mistakes. In which case, did the author feel she had one more lesson to teach, several years after she had retired from her work in the university sector? Was the distribution of the diary, again on some level at least, the execution of a didactic ambition? Susan continues:

"As I read it through, I wonder if the change I hoped for had taken place over the 40 years. It is much easier now, standing back from this time in my life, to be more objective about what I wrote and to see how a person who had travelled it with me might have enabled me to understand the implications of what was being said. Now I can be as objective as is possible in retrospect…

"I am reminded that I need to be aware that my reflection on an event a while ago will have changed with the passage of time and my life's experiences.The knowledge I gained by teaching reflective practice to students all my working life means I have acquired more awareness, which affects my interpretation of the emotional state at the time of writing my diary."

The next section sees the author returning to the roots of the project – albeit a project that had at the time, no grander goal than to capture her thoughts on a difficult period. This is Susan today writing about the Susan at the start of the diary, explaining its exegesis.

Reflection 1:Susan (2024) on Susan (1982)

After two and a half years of being unwell, it was suggested by a friend and colleague, Dr Chris Johns (cf. Johns, 2022), that I should put pen to paper and express how I felt about my experiences. This would, he thought, enable me to come to terms with all that has happened, and perhaps prevent me from reliving some the incidences again.

While continually wondering why I, somebody reasonably intelligent, was unable to communicate to the doctors how I really felt, I believe I was naive about what they said to me, and I will never know how they were communicating between themselves. Hopefully, when I have finished, I shall not want to keep putting the clock back, and I shall learn to accept what has happened and live within my limitations.

Firstly, I must mention that if I had not had such an understanding GP (General Practitioner – family doctor) I would not have remained sane. He had known me for many years. My friends and family have been marvellous, but they are not aware of all the details that I wrote, as some things remain very personal.

Until 1982 the only problem I had ever suffered was migraine since I was about 18 years old, and prior to this I had always had headaches at school. Teachers used to think it was a cheap excuse, although I did not miss any school days. From 1972 my migraine had been reasonably well controlled by taking Dixarit and Stemital.During the years I had many forms of treatment, and more recently after changes in consultants.

What are Saturated Spaces? David (2024)

At the point of feeling the internal spark crucial to the beginning of a long-term writing project, I had published two academic books and a third was well underway. The first, *Fragile Learning: The Influence of Anxiety* was on barriers to adult learning (Mathew, 2015) and the second, *The Care Factory*, was on notions of care inside settings not normally considered to be care settings – for example, in university education, children's prisons, in nostalgia (as a concept) and in the act of creating characters while writing fiction (Mathew, 2016). The theme of my third academic book, *Psychic River: Storms and Safe Harbours in Lifelong Learning* (Mathew, 2019) is probably evident by the title. It is about the joys and frustrations of lifelong learning, and about what drives us to learn as we move through our years. It follows the life-in-learning, from birth to death, of a character that the reader is invited to create. The process of learning, I submitted, is a unique, existence-long walk along a river that understands you and which you long to understand in return.

Throughout these books (and elsewhere), I had formulated ideas about learner anxiety and the Pedagogic Third (the co-created 'third' person in a room of two people) that had served me well, and which had developed into an idea that I had started to call *saturated spaces.* When Susan wondered if I would be interested in working with her diary, the themes of learning and care were of interest – of course – and I could also see the spaces around me (figuratively speaking) thickening with potential life. What, then, *are* saturated spaces? The following extract is from *Learning and Long-Term Illness*:

> Perhaps a few clues are found in what is written above. The time between events that seems drenched with ideas and possibility, but not necessarily while we are living through them: for example, the decades since Susan's beginning the diary and her relocating it by what we have called an accident.
>
> (Unconsciously, had something led Susan to that place of rediscovery?)
>
> The ideas that one has that one explains as being of *just the right time*. The spaces between two authors, when we are apt to use phrases such as: *of the same mind.* The recognition of one's younger self through more experienced and perhaps more nuanced eyes.
>
> Even if the gap between two points is two seconds wide, there exists a *saturated space* between them that establishes these points as goalposts for the future. Whether we wish to accept the truth or not – or indeed, if we recognise the signs or not – any space abandoned is likely to emerge as a hideaway or goal in the near future.
>
> All of us, in one way or another, return to those gates that we opened, where we were offered choices of path as soon as we'd shuffled through – somewhere between a hard left, the path facing forwards, or a right-hand turn that feels unsupported in a way that we cannot comprehend, or even describe.
>
> Of course, forty years is a good stretch of time to have passed before we squint back at earlier iterations of ourselves. There is something satisfying about the

> milestone of *one decade*, let alone *four,* and perhaps even more so when the years involved are solid even numbers. If one of the years of intense speculation that forged this book happens also to be a euphemism for “good vision” – 2020 – then the appeal might be all the greater still.
>
> Saturated spaces are ideas that communicate between themselves. These spaces peak of powerlessness in a patient’s words; confessions to oneself, self-deprecating in tone. But these spaces also hold anger as cargo: anger directed at the services that should have protected this same patient. The patient’s words are critical of the caring profession.
>
> Furthermore, we should consider the spaces between readers and authors. Ultimately, it is your decision – you, the reader – to determine how close you are to the authorship of the following submissions, those that are fragile and those that are resilient. It is *your* book, every bit as much as it is ours: we are happy to create *with* you.
>
> Quite likely (to conclude), the reader will have spaces of his or her own to add to this list, as the book progresses. The authors hope so, at any rate. But now, without further ado, we should probably open the diary and read the very first entry.
>
> Let us all share our saturated spaces. There is always room for one more. (Mathew & Sapsed, 2022, pp.12-13)

Reflection 2: Susan (2024)

I travelled through 1982 in to 1983 with more episodes, more warding, more Consultant visits. Doctors thought I was depressed.

I drifted through the year until December, when I had an appointment with a Neurologist at University College London. He was lovely;however, I had an attack when I was there and was admitted. The Consultant was wonderful and enabled me to do my Open University exam in hospital. I passed, and my degree certificate is dated the day before my exam. I was to discover that I had been referred because it was thought I had had a nervous breakdown.

1984 began with no resolution; I was made to give up my last year of my Open University degree, which upset me, and all my committee work. In May I was on holiday in Holland, and I ended up in Purmerend Hospital. After a battery of tests, they confirmed I had Meniere’s Syndrome. I took home a letter to that effect, only to find it was torn up by my neurologist as he disagreed with the diagnosis. Having thought I had found an answer I was desperate.

I was told I needed counselling and if I did not go my job would be terminated. My medication was discontinued then restarted. And I was sent for counselling. My counsellor said my trouble was that I had not got over my sister’s death, which was in 1974. The medical staff felt I was acutely depressed, but I knew I was not, I was ill. Despite this, I wrote with my sister a short history of my church.

August, I attended the International Conference for Midwives in Sydney much against my manager’s advice. I had an episode at the conference. This led to being seen at the Royal North Shore by a Consultant who was one of the speakers and saw me when I was ill. I had several tests which showed I did have Meniere’s Syndrome and he recommended that I should see my local Consultant when I returned. Nothing happened.

My London Neurologist still felt it was within my own power get to better. So, over the next few months I was in and out of hospital, both locally and in London.

1985 came and went.

January 1986, and my local Consultant sidestepped the system and referred me to a Consultant at the Royal London Hospital. It took one hour to confirm the diagnosis and arrange surgery six weeks later. I had a labyrinthectomy. It took me 18 weeks to learn to walk and still to this day my balance is affected.

Finally in February 1994 I joined the University of Bedfordshire and worked until my contract was not renewed because I did not have a PhD.

I met David Mathew in 2010 when he started work at the University. We started to write papers together, some of which were delivered at conferences abroad, and it was, perhaps, only logical that we would one day work on a book together. I thought it would explore some of the issues I had faced and found very difficult to comprehend. David explored some of these issues using his ideas around Saturated Spaces.

An UnexpectedContribution: Rev. Andrew Fielding

Although there are many additional examples of how the years covered by the original diary affected Susan (many of them interpreted by David), the two authors made the decision to refer the reader to *Learning and Long-Term Illness*to read more,rather than reproduce text from that volume at length here. Indeed, this might have been the end of the story (for now) except for an unexpected(and wonderful!) contribution from a colleague and friend of Susan's who had read the co-authored book. Given that his comment is a review in the form of a reflection of his own, Susan and David had no hesitation in inviting him into the proceedings. Andrew wrote the remainder of this section:

> *Learning and Long-Term Illness* consists of an educator's diary along with later comments and reflections and is presented as a learning opportunity for healthcare workers. I think the book is what it is because of the passage of time after the events. This means there is always hope for learning and healing in every situation if one takes the longer view. The important thing about the phrase "learning and healing" is that it does not mean that the adverse experiences in question were somehow "right," or "meant to happen". It is rather that to be true to one's profession, there is an obligation to overcome them, and to do so in a way that broadens the scope and quality of healthcare going forward. The book suggests, I think rightly, that in undertaking this process, angers and guilts are diminished to manageable proportions.
>
> My understanding of psychoanalysis is scant. However, some authors in this field, cited in the book, gave me much food for thought, opening up enquiries for me I have never really considered regarding pastoral care.
>
> The Introduction and Part Two were for me an investigation into the hermeneutic task. This, of course, is relevant to my seeking useful interpretations of the sacred texts. By useful I mean helping others to better understand the text in order to uncover new and creative directions to take for responsibilities, intentions, meanings and faith. The book's discussion on how the diary is read and reflected upon introduced authors and fields of discipline other than the ones I am used to.
>
> I liked the notion of "saturated spaces". The hard rock of experience, at a later stage, may be struck to release (unexpectedly) a fountain of ideas and possibilities for new work, new insights, new healing.

> Journaling is a necessary part of reflective practice. Specifically, the book has shown the worth of revisiting one's journal after a relatively long length of time. Yet, I do wonder if health professionals would generally do that. It is often the case that last year's diary reflections are to be forgotten in the quest to keep moving on.
>
> I may have missed it, but perhaps the book could have had more to say about the caring (or non-caring) system every healthcare worker finds themselves within. It seems that the system stands over and against the individual or the working group. The system disrupts the staff team, the nursing-patient relationship. It's an old theme, but does the annual review best serve the staff member or the system? Somewhere, the book states that over the past decades, not much, if anything has changed regarding mutual care among staff members and between staff and patients. How is that one cracked?
>
> The Appendix was very helpful and helped ground what care actually can be in a variety of health settings. In answer to the hanging question of the last paragraph, the Appendix sheds light. The caring healthcare professional will never give up weaving the threads of reflection and healing through their life's work. One can hope this will cause a tipping point in the system itself.
>
> I do think it would be helpful if this book, or some form of it could be readily studied by hospital chaplains. Caring is a human quality present in every social setting. Yet it can be either suppressed or freed to flourish. The fate of caring in healthcare is a legitimate and necessary interest for chaplains. This book will assist them to reflect on their particular contribution to care improvements in the hospital.
>
> *Rev Andrew Fielding*
> *Retired part-time Hospital Chaplain*

Reflections on Feelings in Healthcare: Rev. Andrew Fielding (continued)

I am intrigued by two of Susan's questions. Firstly, she wondered why she, somebody reasonably intelligent, was unable to communicate to the doctors how she really felt. And, secondly, she asked: *What does caring do to the practitioners who care?*

The paper is replete with examples of feelings. Frustration, loss, joy, pain, self-deprecation, satisfaction, anger, desperation, struggle, ambition, inertia, failure and success all appear. The book, *Learning and Long-Term Illness*, also mentions guilt. I want to suggest that attempts to answer Susan's questions include recognition of feelings. By this I mean that it is not enough to simply identify them by name. What people really feel is influenced by time, place, culture, and by their position in human power structures at that moment. What did frustration feel like for the hospital patient forty years ago, in that ward, with that medical team, being a vulnerable practitioner among those invincible practitioners? And what does frustration feel like to the same person today who can't get a phone app to work? The same word – *frustration* – is used, but it is felt differently. This is not to belittlethe severity of the hospital patient's experience. But it does show that a person's use of the word "frustration" can be, and too often is, readily misunderstood by the hearer.

Letus take it as self-evident that in human interactions, the transmitted feelings of one, to some degree, effect the feelings of another. My wife loses her ring and is upset. How can I not be upset? Yet I say that it is in the bedroom somewhere, and I am hopeful we will find it. She begins to feel optimistic the ring will be returned to her finger.

Why was Susan unable to communicate to the doctors how she really felt? They shared the same time and place. One can surmise that as health professionals, they even shared the same culture. However, their different placings at that moment in the healthcare system and its spectrum of power ensured no shared meanings of words, and therefore no effective communication. Why is this?

Rob Boddice has written a remarkable book, *A History of Feelings*. In Chapter 5, he outlines changes through the 19th Century inhow surgeons and doctors felt, and how others expected them to feel. How could one slice into a man, causing pain, even if it saved his life? Was this cruelty? Well, yes, men are cruel, but cruelty is all around. The surgeons, in fact, feared a different judgement. Callousness. A hardened heart was needed to witness the patient's pain and still perform professionally. In Victorian Britain, a hardened heart meant to disobey the feelings and conscience God has given everyone. The surgeon carried with him the mark of insensitivity. With the advent of anaesthetics, and the disappearance of pain in operations, the opprobrium of callousness diminished. But it seems the practice of insensitivity continued.

Today, in a healthcare system that is increasingly technical, heavily procedural and fine-tuned for certain outcomes, there is little or no motivation to let a patient's concerns alter the set caring path. I have experienced this myself with my granddaughter, She was taken to hospital several times, unable to feed without crying, choking and vomiting. The hospital decided that her mother was not able to feed her baby properly, in spite of being told she hadsuccessfully cared for and fed two other children. Eventually, a visiting consultant diagnosed tracheomalacia and malrotation of the gut. The consultant said that my granddaughter could have died. My daughter received no apology from the staff regarding their accusations towards her.Many healthcare professionals still carry with them the mark of insensitivity. Insensitivity is no longer a sign of callousness but is nowexperienced by the caring practitioner as a virtue, thatof conforming to and upholding the health system's functional methods. Perhaps this is what caring does to the practitioners who care (or some of them).

I think that the role of feelings, how, and who expresses and receives them in each situation to effect better communication, is a fruitful area of study for caring professionals.

Conclusion

Why does one write about one's experiences? What is the purpose and function of committing our thoughts to a diary that will have no guaranteed readership (in the normal course of events)? Perhaps the co-writing of a book will serve similar purposes as the writing of the original diary had served: that of self-preservation and a willingness to learn and teach. After all, two people were involved in *Learning and Long-Term Illness*, and both seemto have learned plenty from a series of events that anyone might view as negative. Furthermore, the writing is what gives us purpose; and as Klinger (2017, p.13) informs us: "The human brain cannot sustain purposeless living. It is not designed for that. Its systems are designed for purposive action. When blocked its systems deteriorate and the emotional feedback from idling these systems signals extreme discomfort and motivates the search for renewed purpose, renewed meaning."

Life gives us work to do, and purpose gives us the motivation to complete the work, whatever that may be. It is hard to have faith in yourself, but you will win through in the end. Life is a balance of enjoyment and struggle, ambition and inertia, failure and success, gain and loss; and work, by definition, is intended to be the achievement or execution of something difficult in order to earn – primarily financially, but also emotionally, psychologically and perhaps even spiritually (for some). Standing alongside the extrinsic motivation of a salary are any number of examples of intrinsic motivation – the willingness to do a good job, for example.

These are all important considerations.

Reflective Postscript: Susan (2024)

Despite many years of discussing improvements to communication in health services, we have not achieved our aims. Last year Prof Amit Patel 43 had a rare condition in which he was the expert in the field a form of Still's Disease was not believed when he said he need a specific treatment and was let die. In October last year I was told I had aggressive Macular Degeneration. My first visit to the hospital doctor lasted four minutes, to be told the diagnosis: I would go blind. I needed to decide, if I had my small cataract out and he would see me in three months. It was a good job I already knew about the condition, but what if I had not? My sister found herself in a New Zealand hospital after my brother-in-law was taken ill and told he had cancer. The doctor came in and said to my sister, in front of her and her husband: Do you know your husband is dying and has three weeks to live? – and left the room!

Although these are but two examples of recent poor practice when it comes to communication, they are (we hope the reader will agree) two serious ones. Two examples that suggest, despite the excellent practice that undoubtedly exists, that the passing-on of bad news remains an area to be improved, and not only in the United Kingdom. Two books that should be compulsory reading for healthcare professionals – or at least on lists of recommended reading – are Patrick Casement's *OnLearning from the Patient* (Casement, 1985) and *Further Learning from the Patient* (Casement, 1990). Furthermore, the second chapter of *The Care Factory* (Mathew, 2016) is 'Banquet of Crumbs'. If care can be experienced in any setting and at any time, is there anything that *happens to those who care* that we might regard as generic? What does caring *do to the practitioners who care*?

I wish that a different book had been written while I was unwell.Hill & Sharp's*How to Stop Overthinking*(2020) is subtitled*: The 7-Step Plan to Control and Eliminate Negative Thoughts, Declutter Your Mind and Start Thinking Positively in 5 Minutes or Less*. The authors consider the problems over thinking when you cannot seem to get something off your mind and you take it to bed; it then becomes intrusive and uncomfortable, even impossible to resolve. They suggest you focus on what you could do, for example my diary; and thinking about any positive and constructive thoughts you may have will lead to a different picture and a more positive way forward.

Matha Law. The Government gave Royal Consent at the beginning of the month, June 2024 that a patient or relative had the right to ask for a second opinion. Previously it could only happen if your consultant thought it was necessary.

This is will hopefully enable patients or their relatives to know if the care being received is the correct type and alter a feeling of helplessness.

References

Boddice, R. (2019). *A History of Feelings.* London:Reaktion Books.

Casement, P. (1985). 2014. *On Learning from the Patient*. Hove. Routledge.

Casement, P. (1990).*Further Learning from the Patient*. Hove. Routledge.

Hill, C. & Sharp, S. (2020).*How to Stop Overthinking: The 7-Step Plan to Control and Eliminate Negative Thoughts, Declutter Your Mind and Start Thinking Positively in 5 Minutes or less*. 2nd Edition. London: Ingram Spark.

Johns, C. (2022).*Becoming a Reflective Practitioner*. 6th Edition. London. Wiley Blackwell.

Klinger, E. (2017).*The search of meaning in evolutionary goal-theory perspectives and its clinical implications.* In P.T.P. Wong (Ed.).*The Human Quest for Meaning.* London: Routledge.

Mathew, D. (2015). *Fragile Learning: The Influence of Anxiety.* Newcastle: Cambridge Scholars.

Mathew, D. (2016). *The Care Factory.* Newcastle: Cambridge Scholars.

Mathew, D. & Sapsed, S. (2022). *Learning and Long-Term Illness: Saturated Spaces*. Newcastle: Cambridge Scholars.