

**Reflecting on Reflections:  
A Conceptual Revisit to  
“*Learning and Long-Term Illness*”**

**Learning and  
Long-Term Illness**  
*Saturated Spaces*

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**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?**

**This paper tells the story of the discovery of a diary  
penned four decades earlier (beginning in 1982),  
which covered my experience of being diagnosed  
with Ménière's Syndrome.**

**The aim of the book is to share and educate.**

# Learning and Long-Term Illness

*Saturated Spaces*

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I have known David Mathew since 2010, we have worked together. Result was a book - *Learning and Long-Term Illness: Saturated Spaces* was published in 2022.

- ▶ It is 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 book.**

- ▶ **The aim of our book is to look at the course of and illness and the care and suggest ways of it being reviewed.**
- ▶ **Observation and suggestions are made.**
- ▶ **We would be interested in what you feel.**

## After two and a half years of being unwell...

- ▶ **It was suggested by a friend and colleague, Dr Chris Johns, 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.**

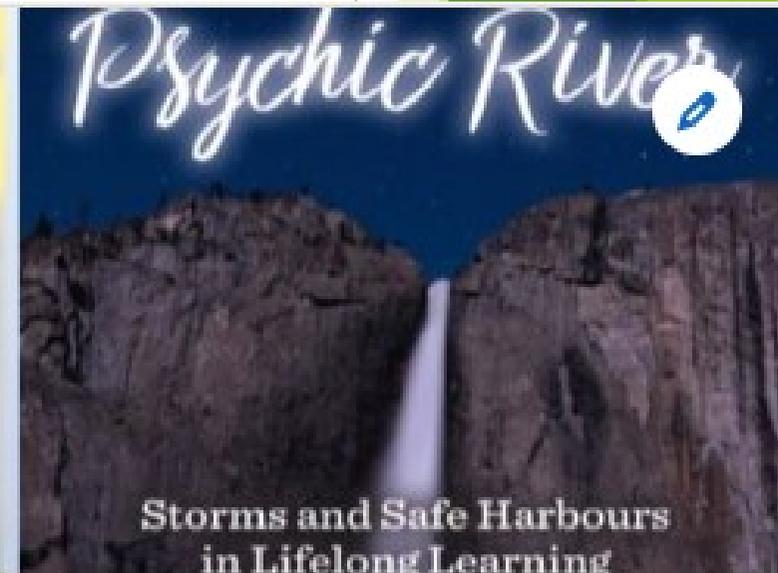
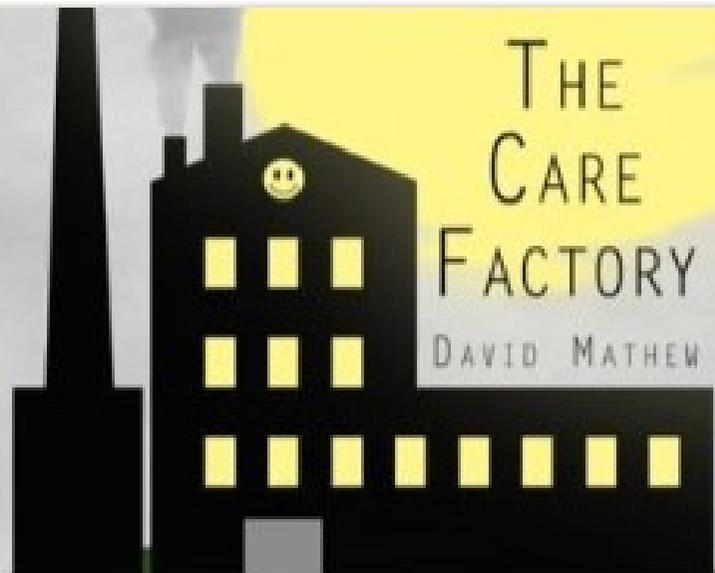
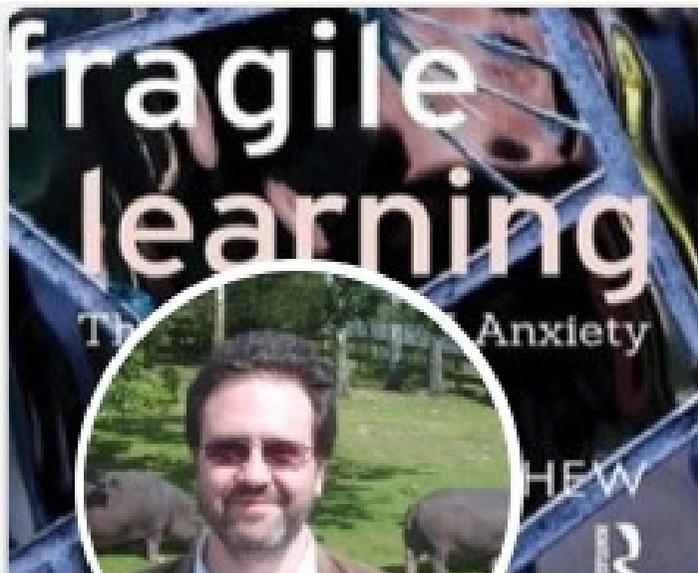
## **Why I kept my diary in those days I am not quite sure.**

- ▶ **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.**
- ▶ **How did it start?**
- ▶ **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.**

**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...**

David Mathew had written several academic books including: *Fragile Learning: The Influence of Anxiety* and *Psychic River: Storms and Safe Harbours in Lifelong Learning*.



## Saturated spaces

- ▶ **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.**

**In May 1984 I was on holiday in Holland, and I ended up in Purmerend Hospital.**

- ▶ **After a battery of tests, they confirmed I had Ménière'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.**

- ▶ **August 1984 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.**

**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.**
- ▶ **Worked until my contract was not renewed in April 2014 because I did not have a PhD.**
- ▶ **Experience counts for nothing.**



## The System!

- ▶ Many healthcare professionals still carry with them the mark of insensitivity.
- ▶ Insensitivity is no longer a sign of callousness, but is now experienced by the caring practitioner as a virtue, that of 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).

## **An Unexpected Contribution: Rev. Andrew Fielding**

- ▶ **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.**

## Andrew writes:

- ▶ 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?



**Andrew writes:**

**“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.**

# Has nothing changed.

- ▶ **2023 Prof Amit Patel 43 had a rare condition in which he was the expert in the field a form of Still's Disease.**
- ▶ **The inquest said had they listened to him he would still be alive.**
- ▶ **2023 October I was diagnosed with Macular Degeneration.**
- ▶ **My consultant told me the diagnosis saying there was no treatment I could possible loose, my sight in 2 years. I had a small cataract he would see me in 4 months. It took 4 minutes. Where was the care?**
- ▶ **2024 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!**

## Way forward

- ▶ I wish that a different book had been written while I was unwell one that showed the awareness that I can now see.
- ▶ I would recommend this book: 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.*
- ▶ This book has shown a person who is unwell needs a supportive person to help interpreted the communications.
- ▶ I hope the book will enable understanding of the patient's perspective – it seeks to add understanding.
- ▶ UK 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.

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**Thank you for listening.**

**▶ Any Questions?**

