

# Learning and Long-Term Illness



# Learning and Long-Term Illness:

*Saturated Spaces*

By

David Mathew and Susan Sapsed

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By David Mathew and Susan Sapsed

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**David Mathew** dedicates this book to Dr Neil Hopkins, Des Lewis and Philip Beckwith.

He also thanks the colleagues who are quoted in a series of interviews in the Appendix. Although the interviewees' identities must remain "off the record", their contributions are no less appreciated.

**Susan Sapsed** dedicates this book to Dr Peter Norrington, and would like to acknowledge debts to her GP, Dr Gardener, Mr Kapadia, Mr Pedlow, Dr Stern and Professor Morrison.

“May it resound with the right note here where I am placing it, between the before and the after, even if it demonstrates that the after was kept waiting so that the before could assume its own place.”

—Jacques Lacan, ‘Logical Time and the Assertion of Anticipated Certainty’

“Chance is always powerful. Let your hook be always cast; in the pool where you least expect it, there will be a fish.”

—Ovid, *Heroides*

# CONTENTS

Introductory .....	1
Buried Words and Raised Voices	
1 .....	1
2 .....	1
3 .....	6
4 .....	9
5 .....	12
Part One.....	14
Opening the Diary (1982-1984)	
Extract 1: Being a patient in a caring society.....	14
Comment .....	14
Extract 2: July – December 1982 .....	16
Comment .....	21
Extract 3: 12 <sup>th</sup> January – 28 January 1983 .....	23
Comment .....	25
Extract 4: Nursing care .....	26
Comment .....	27
Extract 5: Visitors.....	28
Extract 6: February – July 1983 .....	29
Comment .....	31
Extract: OU Course .....	34
Extract: July 6 <sup>th</sup> – 22 <sup>nd</sup> 1983 .....	35
Comment .....	37
Extract: Nursing staff.....	39
Extract: Visiting.....	39
Extract: 11 <sup>th</sup> August .....	40
Extract: 11 <sup>th</sup> August – 13 <sup>th</sup> September .....	41
Comment .....	42

Extract: Depression.....	43
Comment .....	43
Extract: Passing the time .....	44
Comment .....	45
Extract: 14 <sup>th</sup> September – 30 <sup>th</sup> November .....	46
Comment .....	47
Extract: 1 <sup>st</sup> December – 17 <sup>th</sup> December 1983 .....	48
Comment .....	54
Extract: January 1984 .....	55
Extract: 5 <sup>th</sup> January – 10 <sup>th</sup> April.....	55
Extract: 26 <sup>th</sup> April – 3 <sup>rd</sup> May 1984 .....	57
Comment .....	61
Extract: 10 <sup>th</sup> May 1984 .....	61
Extract: 17 <sup>th</sup> May – 25 <sup>th</sup> July .....	62
Comment .....	64
Extract: August – December 1984 .....	65
Part Two .....	67
Learning from Long-term Illness	
1. ....	67
2. ....	72
3. ....	74
4. ....	77
Part Three .....	78
Broken and Saturated Spaces (1985-1993)	
Extract: January 1985 .....	78
Extract: 25 <sup>th</sup> January – 5 <sup>th</sup> February.....	79
Comment .....	88
February – March 1985 .....	89
Extract: 27 <sup>th</sup> March 1985.....	90
Extract: 4 <sup>th</sup> April 1985.....	91
Extract: 26 <sup>th</sup> June 1985 .....	92
Extract: January 1986 .....	99
Extract: January 9 <sup>th</sup> .....	99

Extract: 10 <sup>th</sup> January .....	102
Extract: 14th January 1986.....	103
Extract: 11th March 1986.....	104
Extract: 16 <sup>th</sup> March 1986 .....	105
Extract: Nursing staff.....	112
Extract: 1st April – 4th July .....	112
Extract: 7 <sup>th</sup> July – Back to work.....	116
Extract: 24th July .....	119
Extract: Autumn 1986.....	120
Extract: 1987.....	120
Extract: 1988.....	121
Comment .....	121
Extract: 1989.....	121
Extract: 1990-1992 .....	121
Extract: July 1993.....	122
Extract: August .....	122
Epilogue: Luton.....	122
 Part Four .....	 124
Treatment’s Bluff: Emotion and Guilt	
Professional Guilt .....	124
...But What is Guilt?.....	125
Cognitive Dissonance.....	128
My Own Professional Guilt (Susan Sapsed).....	128
Writers on the Subject of Guilt.....	130
Reflection.....	131
Mindfulness, Diaries & Psychoanalysis.....	133
 Postscript.....	 135
Closing the Diary	
1.....	135
2.....	135
3.....	136
4.....	137
5.....	138

Epilogue ..... 140  
A Journey North: Canterbury to Leighton Buzzard (2017)

Appendix..... 141  
Interviews with Healthcare Educators (David Mathew)  
    First Interview: Senior Lecturer in Children’s Nursing..... 141  
    Second Interview: Senior Lecturer in Mental Health Nursing.. 146  
    Third Interview: Senior Lecturer in Adult Nursing..... 149  
    Fourth Interview: Senior Lecturer in Midwifery..... 152

References & Bibliography ..... 158

## INTRODUCTORY

### BURIED WORDS AND RAISED VOICES

#### 1

Although there are ghosts in these pages, they need not distress us.

To live with hauntings is in part to recognise memories; and the acknowledgement of individual memory is but one of the anchors that holds this narrative in place.

However, an early question must follow: *whose memory is under discussion?*

Such a question takes us to the subject of authorship, and to the fact that although there are *two* names on the cover of this book, there are *three* authors present in and above the narrative. Or should we say, *at least* three?

Your *obvious* authors are David Mathew and Susan Sapsed, who are here as one person each (notwithstanding the alternative versions of ourselves that we might present from time to time). Your third author is *also* called Susan Sapsed. This is because Susan appears in these pages at two different points in her life. In fact, four decades separate the versions of Susan that appear in these pages.

Or should we say, *two of the versions* of Susan that appear in these pages?

#### 2

Between July of 1982 and July of 1993, the earlier iteration of Susan Sapsed kept a diary that will be referred to throughout this book. Indeed, the diary is the source material for *Saturated Spaces* and the reason that the book has reached publication. Susan began this

diary when she was 37 years of age. Referring to her reasons for beginning the diary at this age, the Susan writing in 2021 suggests an impetus based on reasons of personal illness, practitioner misunderstanding, patient frustration and familial loss. These ingredients are likely to become clear in due course. For now, by way of an early introductory summary, we will say that Susan had become convinced that she was suffering with Ménière's disease. This is a disorder of the inner ear that often leads to dizzy spells and hearing loss for the one so afflicted. Of these early days in the composition of the diary, my contemporary co-author writes:

*I came back from Holland with a definite diagnosis, and nobody would believe me, even though I had all the paperwork. When I first visited Dr. A. [see below], she tried to suggest that all my problems came from not dealing with my sister's unexpected death in 1974. My sister died in less than 24 hours with septicaemia. That was when I felt I was fighting a losing battle. How would I make everybody believe that I had Ménière's.*

*I came home after my first visit in quite a state, possibly made worse by the trains being even more delayed that day. In the evening I should have gone out for a meal but cried it off. During that evening, a friend from work called and she realised how I felt and suggested the only way I would be able to come to terms with how I felt and begin to move on was to write down how I felt. As time progressed, she would occasionally read what I had written, with no comment.*

To secure an early glimpse into the frame of mind that will follow in these pages, perhaps we might examine the author's reason for committing her thoughts to a diary in the first place. "I kept a diary at times when my mum was ill," Susan clarifies, decades later...

*which was often when I was little. Over the years I have also written up several holidays: for example, my first journey abroad; the opening of the scout hut in Scotland; and some of my overseas visits, like Australia and New Zealand. It is a bit spasmodic. I wrote*

*reflexive accounts of my knee and shoulder injuries: I think, in order to make sense of what was going on in my life during those times. But in general, no, I do not keep a daily diary. I only record events when I feel a need to do so.*

Let us keep in mind, as we read together, these concluding words: *when I feel the need to do so*. Of what ingredients would this need be composed? What the diary was trying to say – and what we make of it decades later, from a modern standpoint – is part of the reason for our collecting our thoughts in one place.

Of course, people tiptoe their tentative first steps into their diaries for any number of different reasons; but it is surely worth mentioning that the diary under consideration had its author's personal distress as its literary midwife. If we are to trust Montherlant's famous declaration that happiness writes white – it does not show up on the page, because happiness cannot be anchored down and articulated: the exquisite and the blissful rely on wordlessness – then allow me to be clear from the outset: there is little snow-white font in the pages that follow. 21<sup>st</sup> Century Susan and I have looked at a diary that was written in the midst of physical pain and emotional discomfort.

Nor was the recent "literary midwife" metaphor an idle comparison. Susan herself had worked as a midwife for some years; at the time of the earliest submissions to the diary, she had taken on teaching roles as well. Professionally (at the time), Susan had occupied a positive space. *Teaching and work were fine*, she writes:

*– excellent groups of students. One of the consultants who guessed what I was going through was very supportive and remained so until he retired. Often when I was an inpatient he would come and sit on my bed and just chat, which was helpful.*

For some, the diary will have a confessional spirit: the submissions – or even emissions – that are tricky to supply elsewhere. Confession is good for the soul, we might agree; but what is a *soul*? Can we agree on a definition for something that

three different people in one room (or three authors of one book) might variously describe as ineffable, implicit and impermanent? Might we use *soul* as a synonym for *conscience*?

The confessional insists on an individual's integrity. In an oblique way, perhaps we might consider a diary an "integrity group", after the American psychologist Orval Hobart Mowrer in the middle of the last century. Mowrer encouraged patients (to join him) to come together to confess sins and discuss subjects that have created guilt; Mowrer played by exactly the same strict rules. (Meetings lasted a minimum of three hours. Group participants were obliged to laser in on any vocal submission that sounded defensive or evasive.)

Is the sharing of such emotional material not the rationale of the diary also? The obvious difference here, of course (if we are to accept the comparison) is that Susan's integrity group has lasted, not three *hours* but three *decades*. The contemporary responsibilities of this book's two authors and its readership are analogously picky and empathetic.

Needless to say, other interpretations pertain; each of them delivers further questions. Such as: Is a diary an intention to forget? Or rather, is the completion of a diary an intention to forget? By writing in the pages of a diary we attempt to anchor our thoughts and emotions to a time and space. Having done so, we are at liberty to lose mental sight of what we have deposited. We know we can go back to the record if we need to. The following extract is not from Susan's diary but from David's notebook (written in 2020):

*When I look at Susan's diary, I am aware that only one other person has read it – one person other than its author, of course.<sup>1</sup>*

*Can a diary-writer be said to be a reader of the self-same diary? For many if not most diary-writers, can we assume that there*

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<sup>1</sup> The reference is to our colleague who transcribed the written word into a digital document.

*exists an imperative to deposit but no expectation for one's treasure to be discovered at a later date?*

*She who writes a diary (I submit) is not a reader of the same monograph. Can we imagine the author revisiting the inked page later? Probably not; the idea is surely to capture a moment of a length that might seem indeterminate at the time, but which has already been established by the Future.*

*Surely it is not much of a cheeky stretch to assert that the diary-writer is not given to revise, on a regular basis, the commitment made to paper on the previous evening. Little honing takes place: the whittling of a stick into an heirloom – or even into a functional tool or ornament – is not the purpose of the diary-writer. The instant is what the diary-writer hopes to capture. It does not matter if a mistake is made – an unfinished sentence, a spelling blip, the transposition of two words or a Spoonerised contribution – the important matter is to record the feeling or the event with the urgency, and perhaps the simplicity, of a response to an alarm.*

*I cannot imagine Susan poring over the entries that she made in her diary, decades earlier. The thought of returning to buried words ... is unappealing at best.*

Is the completion of a diary the storing of psychic treasure? Do we hope to find our words later? Do we hope to share those earlier experiences – the thoughts and impressions that we buried beneath the sand – when we make this eventual discovery? Does the writing of the diary constitute a contract with oneself... and a self-analysis? We might turn to Wilfred Bion for an interpretation at this point. In *Four Discussions with W.R. Bion* (Bion, 2018), a questioner asks: "If the patient knows what he is doing and you know why he is doing it, why interpret what he is doing other than asking him why he is doing it?" Bion replies:

This is another mystery. Why not pass it over directly from himself to himself? Why is an external person necessary? Why can't the

human being be like lumbricus?<sup>2</sup> Why have a partner at all? ... Why can't one have a relationship with oneself directly without the intervention of a sort of mental or physical midwife? It seems as if we need to be able to 'bounce off' another person, to have something which reflect back what we say before it becomes comprehensible. (Bion, 2018, p. 49)

If *Saturated Spaces* might be used, as well, as such a bouncing-off board, then this will be a useful function. For sure, this book is intended as a collection of reflections. This book is a set of interlocked lenses; light will flash off some of the surfaces – and other surfaces will permit the reader easy access to what has been contained.

### 3

Has the diary been included in *Saturated Spaces* in its entirety?

No.

Even if space had not been an issue (which it is, with publishing costing what it costs), we would not have presented every one of Susan's entries. Not only does the diary, in full, run to 45,166 words, but – as is often the way with a diary – there is repetition, there are dull bits, and there are periods that are not without interest but which do not conform to the themes of this book; there are redundancies. Therefore, we have attempted to be selective without being biased. While some extracts are reproduced in full, others have been edited for flow and relevance.

For clarity, a note on the presentation of our material is offered at this early juncture. Indeed, the matter of how to present (on the page) the different times and voices was a live concern for several years. Undoubtedly, we could have deployed the strategy of a singular narrative, almost in the form of a novel, with contemporary comments on individual extracts. However, this method would have required constructions such as "Susan wrote in 1985" (for example)

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<sup>2</sup> Genus containing nearly 700 valid species of earthworm.

or “The authors think today that...” – constructions that probably would have become cumbersome – maybe boring – to the reader before very long.

Therefore, we have decided to present our work in the following way. Contributions in italics are extracts from Susan’s diary; each of these will be headed with the word *Extract* and a number. These extracts are interspersed with comments on what we have just read – some short and some long – and the comments veer from confident interpretations and analyses... to blind guesses.

These submissions derive from combinations of interpersonal relationships. Some are based on Susan and David’s relationship with each other (now); some on Susan’s relationship with her earlier self; and some on David’s retrospective long-view of the earlier Susan.

The main body of the text is delivered by David Mathew and Susan Sapsed, composed as it was between 2018 and 2022. Where Susan reflects on an earlier submission, the attribution should be made clear via a construction such as “...Susan reflects now” – or the like. Not many of Susan’s entries in the diary are given an actual heading, other than a date or a (usually specific) range of dates.

We submit that we should note the entries that have their own headings... and ask what the rationale was behind the titling. Was the very early entry, with its no-nonsense, operational title (“Being a patient in a caring society”) to have set the tone for the entire diary? If so, we can only guess why this titling strategy changed. As for the title of the book itself, please read on...

With this unorthodox (not unique, but unorthodox all the same) authorial stance, comes a certain compositional tension. Not that Susan and David shared a single disagreement; they did not. Not even that one or other proffered into the narrative mix a solitary unhelpful notion: again, this was not the case. The creative relationship was amicable... and slow.<sup>3</sup> In the absence of time

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<sup>3</sup> From David’s Notebook: “Some works require an age between what Nabokov referred to as the “initial throb” of creation and some sort of clumsy first-draft expression. Some, a further age between this clumsy first-

pressures – or so much (for a long while) as a realistic expectation of project completion – there was no condensed period in which confusion and miscommunication might have evolved.

The authors worked with blithe spirits; in so doing, on reaching the final milestone of the page leading onto the structured marks in the sane that is the References section, it might be added that the two contemporary authors fulfilled the investments made by a much younger contributor, back at a time when she would have had no idea that she was burying treasure of whose eventual discovery there was no guarantee.

Nevertheless... *authorial tension* was mentioned... and should be remembered. At each stage of the process, the project might have failed; *Saturated Spaces* was the result of patience and belief. Doubts had to be laid to rest. Time – in two busy lives – had to be found and used carefully. While the project had always seemed pregnant with possibility, there were difficulties to overcome ... as indeed there are with most writing projects.

An important early consideration was the following. Inevitably, the topic of the book would lead Susan, and possibly David, into areas of anger and disappointment with some of the younger Susan's professional and therapeutic treatment, and a reasonable concern was if the material was simply too personal to discuss. Would Susan feel strong enough to be honest?

Balanced against such a doubt were a number of countervailing notions. The first was the possibility of "healing" Susan (in fact, *both* Susans) through work and words. Introspection

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*draft expression and completion. Within these broad swathes, some books are the product of dedicated and concerted study between the deposit of the first capital letter and the babyish grunt of satisfaction that accompanies the concluding full stop. Within these boundaries, little other work intrudes – in fact, it is likely that little other life intrudes. Other books use up the same amount of time from start to finish, but are sketched at, picked at, addressed in small bursts and in temporary spasms. Very much so, this current work is an example of the latter compositional model."*

is a leap towards restitution... perhaps. The second notion was that of continuing a writing tradition of our own making.

Prefacing the much earlier paper “The Body in Illness” (in Mathew, 2015), David wrote: “If the idea behind the paper had been to suggest unconscious adherence to two intertwined processes (those of healing and reflection), then it made sense to have these strands woven through the whole work.” Something similar is intended in *Saturated Spaces*.

To explain how the book came about, it is hoped that a brief review of its origins should prove useful to the reader.

#### 4

In 2010, David started work at the University of Bedfordshire, where Susan had been employed since 1994.<sup>4</sup> (Susan had registered as a midwife in 1968 and was concluding her full-time working years at the University; she took retirement in 2014). David’s tasks fell under the overall theme of education development; Susan was a Senior Lecturer, with a responsibility for recontextualising the Masters in Public Health into an online learning programme.<sup>5</sup> Susan and David were paired together to take on this task, and in due course David took their co-authored paper on the subject to an academic conference in Rome. It was the beginning of a writing partnership. Along with further university collaborations, other co-authored papers followed, several of which accompanied one or both of their authors to various parts of the world, and several of which David included in modified forms in the first part of his first academic book, *Fragile Learning* (Mathew, 2015).

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<sup>4</sup> Coincidentally, the same year that David accepted his first teaching appointment, having graduated in 1993.

<sup>5</sup> Writing here and now – well over a decade later – it seems retroactively odd (perhaps) to recall a time when online learning felt new and exciting; when it was regarded, indeed, as a *choice* for the future, long before a pandemic rattled our global cage and our collective pedagogic complacency.

Among those co-authored papers were accounts of an injury that Susan sustained many years after the earliest of the thoughts under discussion herein were committed to Susan's small hardback diary.<sup>6</sup> The tone in these later accounts was informative – confessional, perhaps. To David, as he worked with some of the raw material that Susan handed him, it was apparent that there existed more than one motivation.

Of course, there was the simple to get published; as many of our readers will agree, being published – and acting on the impulse to *get* published – are two potent and interlinked motivations. However, as has been mentioned, it seemed to David that Susan's mingled authorial tone – which splices together personal experience, the drive to share in order to teach others, and a longing to expose flaws and establish alternatives – was very much in keeping with what was in the diary, seen by both parties many years later after it had been imagined lost by Susan.

The diary was found in 2017. Susan's purpose for informing David of this find was to highlight, in a joking manner, the embarrassment that she had experienced on re-reading the document (and in some cases, decoding some of her own script). Susan and David had continued to meet for coffee after Susan's retirement, and the diary – to begin with – was a subject to discuss at one such meeting. It was David who imagined that the diary might

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<sup>6</sup> A co-authored paper entitled 'The Body in Illness' begins in this way: "Illness and trauma are part of everyday life and can have significant impacts on our lives and the people closest to us. It is therefore necessary to consider such events and their consequences in the contexts of our life-wide experiences through which we learn and develop, however painful and uncomfortable they might be. The question that we are interested in is: can reflection help to heal and enable us to move on after failed surgery?" Perhaps this gobbet will provide the reader with an idea of the tone and style that are mentioned in the main text. A revised take on 'The Body in Illness' was published in *Fragile Learning* (Mathew, 2015). As was written in that book: "In other words, both Susan and I are responsible for the next section, but it is very much Susan who had endured the pain" (Mathew, 2015, p. 83).

have a further purpose; even as early as that very first introduction to this monograph, he began to forge ambitions for its future use and a new writing project. Several years later, David reflected on that period of initial interest in his own journal. The entry reads:

*I wondered then and I wonder now, in retrospect, if unconsciously Susan had passed the diary to me as a way of continuing the story – which was fascinating – in the hopes of getting it out to a readership, however modest. For it is indeed an unusual document. It is an almost forty year-old account of being in the long-term care of a health system that seemed to struggle with some basic concepts of dignity and decency, written by a woman who taught health matters at university level, and who had taken a reflective stance in her own work for some time.*

*It was only after we had concluded our meeting that I began to wonder if she and I might collaborate once again on a project. Recently, Susan and I had collaborated on a short conference paper that Susan had taken to Berlin (Sapsed & Mathew, 2016), but otherwise our rate of written production had started to resemble that of a mollusc, especially when compared with several years of fairly frantic and successful co-authoring.*

*Specifically I wondered if there was work to be done from the angle of regarding the past through today's lenses. The fact that the diary chronicled years of its author's chronic pain was also interesting. That Susan, in the present, was in her seventies and largely pain-free was similarly intriguing, and I imagined would provide another important contrast. On a very unconscious level, I had started to forge links between long-term care and lifelong learning, which in turn helped to develop portions of *Psychic River* (Mathew, 2019).*

*I arranged to have the diary transcribed, and work began.*

## 5

Finally, before we open the diary, we should say a few words about the title.

*What are saturated spaces?*

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.

## PART ONE

### OPENING THE DIARY (1982-1984)

“It is obvious that people do not say what they really mean even when they honestly and sincerely say what they consciously think, let alone when they do not.”

—Isabel Menzies Lyth, *The Dynamics of the Social* (1989)

#### Extract 1: Being a patient in a caring society

*After two and a half years of being unwell, it was suggested by a friend that I should put pen to paper and express how I felt about my experiences. This would enable me to come to terms with all that has happened and perhaps prevent me from reliving some of the incidents again.*

*As somebody reasonably intelligent, why was I unable to communicate with the doctors how I really felt? And how could I be so naive about what they said to me, and not add up the various incidents to point to how they really felt and what they were communicating between themselves? Hopefully, when I have finished, I shall not want to keep putting the clock back two and a half years...*

#### **Comment**

In the early stages of *Incandescent Alphabets*, Annie Rogers offers the following:

To enter this project fully, I not only have to read and immerse myself in the experiences of others I have never met, I have also to keep company with my own past. (Rogers, 2016, p. 2)

Let us think of these interconnectivities – and these claims of solitary working.

In this inaugural submission we see the reflective stance and the defiant/deflated mood that will come to seem trademarks of Susan's writing. We can also sense that the patient felt that odds were stacked against her, somewhat; and that she had been disadvantaged by poor health care for far too long.

Christopher Bollas states that “we are witness either to the emergence of a new emphasis within personal illness or we are just getting around to perceiving an element in personality that has always been with us” (Bollas, 1987, p. 135). Not one word of this do I doubt or question; however, I submit that Susan's case is both what Bollas describes and then a development on from the same. Not only was Susan, even at this early stage, a patient well-versed in the ways of the National Health Service, she was also a critical thinker, a midwife and a teacher. My contention is that she knew what she was receiving was insufficient, but that she also blamed herself for not receiving better service.

The paradox is poignant. Susan would have known how to provide good care, and yet it sounds as though she is punishing herself for not *receiving* a good service – she implies that she does not deserve it. Perhaps she has split off an unwanted part of herself and projected it onto the caregivers who were employed to look after her.

It could be that she blames herself for something, on an unconscious level, and the healthcare providers – in their caring manner, almost – are satisfied to accommodate Susan's projection. Via the mechanism of projective identification, the caregivers become what the patient does not consciously want them to be but unconsciously wants them to be, in the sense that they take on something that Susan herself does not wish to carry around any longer.

To turn to literature for a relevant moment, Alice Thomas Ellis has the following to offer: “Just as the healthy think the ill are

malingering, the ill think the healthy haven't yet recognised their own symptoms" (Ellis, 1980, p. 22).

We might do well to bear such a thought in mind as we proceed; but we also have Susan herself, today, to comment on this first entry. "I felt even from the beginning they were not listening to me," she now believes, "only reading the referral letters. What did they say?" At the time there was no participation. You were the patient, and they knew best!"

Let us keep in mind the notion of a patient co-owning the responsibility of participating on one's healthcare and recovery. These days, such a co-ownership has been an option for years, but let us always remember that nearly four decades have elapsed. Participation and co-ownership will recur as themes throughout *Saturated Spaces*.

### Extract 2: July – December 1982

*Until July 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 with medication. Since 1976 I had had a problem with my right wrist, which Dr B.<sup>7</sup> had felt could be joint and nerve trouble. In May or June 1982, Dr Y. suggested that I should see Mr W. to see if it was possible that I had a nerve trapped in my neck, which could be the cause of the pain in my hand. I saw Mr W. one Thursday afternoon. Having waited some considerable time, I became very anxious both about seeing Mr W. and about the students I had left for a few minutes. Finally, I was seen by Mr W., who gave me the impression it was a*

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<sup>7</sup> Identities have been protected throughout this book, with the exception of certain professional or personal acquaintances of Susan's, in submissions where that person is specifically praised or highlighted positively. Credit where credit is due, might be shorthand for our decision here.

*lot of fuss about nothing. Like many doctors, he would not know the hindrance it had become, especially in my work.*

*After I had been deposited in a cubicle, he proceeded to turn my head sharply to the left, right, up and down. Immediately I felt dizzy. He said I should have my neck X-rayed, for yet another time, I felt. I had had so many X-rays: all normal. Despite this, off I went to X-Ray. After a delay, I was called, and while I was changing, I felt exceedingly dizzy; never had I felt like this before. I felt sick and I had a splitting headache, but in the left side of my head. The vibrations in my right ear did not seem any more apparent than usual, but my hearing was dull.*

*As the X-rays progressed, I wanted to “die”, because the pounding in my head was excruciating, and every time it was moved it seemed to exaggerate it. The staff were very pleasant and took me back to Outpatients in a wheelchair. I felt dreadful but equally stupid. Nobody could help me. I just wanted to be left alone and not to move, but this was not to happen. Once I had been laid down on a trolley, Mr W. came and said that he had not done anything that could have caused such an episode. Apart from the pain, my right arm felt numb and heavy, and I had difficulty in moving my fingers.*

*Eventually came the end of the clinic and I was asked what I would like to do. All I wanted was to stay still and be left alone. This does not happen in hospitals. One of the staff nurses very kindly wheeled me back to my office in the Residence. I must have sat there for about an hour or more before I felt it would be unrealistic to think of driving home. By now it was now about 7 pm. I rang [a colleague named] Nancy<sup>8</sup>, and she very kindly said she would take me home. Once Nancy saw me, she was not very happy to take me home,*

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<sup>8</sup> Susan explains: “Nancy was a staff Nurse on Special Care. Since the Unit was so small, all knew each other very well and she was aware I was not well, as one day when she was taking a baby into theatre after the op, she asked me what was wrong, so I explained. She felt I should not have been in theatre but there was nobody else who could have done it. Especially as it was with a consultant who could reduce the staff to tears and I had only a new staff midwife with me.”

*because I was so unsteady and my feet and my head pounded so much, not to mention that I could not see, my vision was both blurred and double. Nancy helped me get undressed and into bed before she left me. That night I lay as still as possible; the slightest movement caused great distress.*

*The next day I knew I had to go to work, so I rang Joan, to ask her if she would come and fetch me, which she readily agreed to. On seeing me, she advised me to stay at home, but I insisted, as I felt marginally better. I was all right until coffee time. Then it was as if a second wave arrived. Eventually I agreed that Edna<sup>9</sup> should take me to Staff Health. Mr. W. said I should be taken up to Lemsford Ward (it is the orthopaedic ward).<sup>10</sup>*

*The staff on the ward were not expecting me, so they sat me in the dayroom – with the television, the noise was awful, my ears rung, and I wanted to run away. It was no better when they laid me in A Bay, the noise from the kitchen and the lunches made me feel I wanted to scream.*

*Finally, Mr W. came to the ward, and at the end of his round he came into A Bay, because it was empty apart from me. He had his houseman<sup>11</sup> and registrar, whom he was telling off over a patient's treatment. Standing at the end of the bed, they continued to argue out the situation, to my intense discomfort and great embarrassment.*

*Once Mr W. had made his point, he turned to me and asked me what was wrong. By this stage I was extremely agitated, what I*

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<sup>9</sup> A work colleague of Susan's at the time.

<sup>10</sup> Susan's own clarification of the purpose of Lemsford Ward is interesting. It is in the original diary and suggests an unconscious wish for a readership beyond her own eyesight. Perhaps it is a deposited explanation destined for an older – later – Susan (which intention has obviously been satisfied). Or perhaps it is a deposited explanation for me and for you, the future readers (which, if so, has obviously also been satisfied). The attention to detail in this excerpt would suggest identical interpretations.

<sup>11</sup> A houseman is someone who has nearly finished training as a doctor and is working in a hospital.

*said I do not remember, but I do remember not wanting to move my head. Therefore, when he touched me, the discomfort was probably more unreasonable as I was so tense. The result was that he asked Mrs S., the physiotherapist, to show me how the TENS machine<sup>12</sup> works. It did not seem to do much for my head, but it did a great deal for my wrist. After the treatment, Mrs S. said I should go back to the office, and I would gradually feel better. The staff on the ward said that I was to see Mr W. on Monday.*

*Following an uncomfortable weekend, I saw Mr W., who did not appear to want to know that I did not feel well. He said the TENS had not helped my head because the batteries were low.<sup>13</sup> So, I was dismissed to go to Physio for new batteries, and to continue the therapy, and see Mr W. later in the month. This episode wore off after about four days, but later that month I had another. My appointment came, and I saw Mr W.'s registrar, who was extremely nice and said he could not advise me, since I was under Mr W. So back I had to come to be given a collar to wear.*

*In August I saw Dr Y., who said that since the TENS had helped my wrist, I should continue to use it on a regular basis and then periodically as I felt I needed it. About the other problems he had no answer. At first, I hired the machine, but later I bought one, because with the treatment I can keep my wrist reasonably comfortable, although I am aware of an increasing loss of grip which is more marked today.<sup>14</sup>*

*From August to December, I had four of these episodes, mainly associated with sharp unexpected movements of my head. It happened during my Open University weekend at Harlow; and while away at a friend's, I was swinging her children, this is definitely how it happened. The pattern of what subsequently followed was always*

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<sup>12</sup> transcutaneous electrical nerve stimulation

<sup>13</sup> Susan comments in 2022: "I should have said **Rubbish**, as Mrs S. had fully charged it before she gave it to me, but in my day the Consultants wanted to be treated as gods."

<sup>14</sup> We should probably take "today" to mean the end of the period covered by this extract, i.e. December 1982.

*the same, with the exception that sometimes I was violently sick and at other times I just felt very nauseated.*

*Typical of these occasions was in December, when Ruth, Mary<sup>15</sup> and I were walking into the main hospital via Casualty. Mary was shutting the fire doors so quickly that I moved my head to dodge the door, instantly I felt funny. It was not until our arrival on the fifth floor that I knew another attack had occurred. I was conducted to a side room on Peartree East, which was our antenatal ward, where I sat hoping against hope that it would go.*

*I preferred to sit, which everybody insisted was not right. I should lie down and be more comfortable. I could not make people realise that the back of my head was too uncomfortable. On this particular afternoon, Mr W. said he would see me, and came up to the ward at Ruth's request. When he came up after his theatre list, he had backache, because I was to discover he had hurt his back skiing, and it was obvious he was uncomfortable.<sup>16</sup>*

*Yet again he asked me what had happened and all the usual questions.<sup>17</sup> Although Mr W. was pleasant in his own way, I always found I felt at a disadvantage because he never seemed to want to listen, he was always in a rush... I do realise, compared to a major R.T.A. my problems must seem very insignificant, but that did not help how I felt or that the unexpectedness of the episodes made it very difficult to plan life. It had also made the last few months of my OU course extremely difficult, especially some of the Study Days. Mr*

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<sup>15</sup> Mary was a Midwifery Tutor colleague. "She lived in Welwyn Garden City; on many occasions she was a great help."

<sup>16</sup> In this paragraph is an interesting repetition of the idea of *comfort*. Not only does Susan wish to achieve a state of comfort, but she also cannot make others understand that comfort eludes her. Despite her current indisposition, Susan has also become alive to the discomfort of Mr W., whom we might call her tormentor in at least one sense. Either Susan is displaying empathy (or relatedness), or this is an example of a projective identification. Please see further on in the main body of the text.

<sup>17</sup> "...which over the next 2 ½ years I was to wish I had put on tape!" Susan appends today.