Abstract:
What happens when a place writes itself into our bodies, and when broken bodies write from fractured places? I have been immersed in a sick body after being born into the “kingdom of the sick” (Sontag 2013, p.1) when I was diagnosed with Cystic Fibrosis at nine weeks of age. Consequently, I have spent a substantial amount of time in hospital—a place we go to ‘get better’. My hospital bed is a place I have always written—often with friends dying around me and in the face of immense physical and existential suffering. Being creative in an institutionalised setting has allowed me to resist the feeling of confinement, where I’m able to establish routine and agency to try and create some order among the disorder. The concept of place became especially significant when I was placed in isolation due to being immunosuppressed following a double lung transplant in 1998. The landscape changed from one of community to one that was more solitary and dystopian. A liminality of place exists between home and hospital, and this creative work contemplates how a multidimensionality of creativity can exist, and indeed thrive, within an institutionalised setting.

Biographical note:
Carly-Jay Metcalfe is a Queensland based writer. She is currently studying her Master of Philosophy in Creative Writing at The University of Queensland on a full academic scholarship. Her debut memoir, ‘Breath’ is being published by UQP in early 2024.

Keywords:
Autopathography, illness, narrative medicine, memoir
May I write words more naked than flesh, stronger than bone, more resilient than sinew, sensitive than nerve – Sappho

The hospital (as playground)

The hospital bed is the anchor point of birth and death, those precarious bookends of life. But as I hang upside down on a vertical bed, my eyes survey the park with its rusted-out bus – heaving with tetanus – as I’m pounded on my chest to dislodge the thick and viscous mucous that will kill me.

*

In the 1980s, the doctor-patient dyad is an onerous beast to wrangle. I am seen as a body in a bed – more petri dish and infected lungs than human. Foucault wrote that health can be understood as a discourse, how it “transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart” (Foucault 1998, pp.100-1), but my particular power dynamic is fraught with dehumanisation. In place of my name, I am referred to as my dis-ease. As a child, I assume that doctors have been set a special course on dehumanisation at medical school, for what am I – who am I – if not a set of symptoms to be conquered?

This was the understanding of medicine in the late 20th century. The biopsychosocial model of care didn’t yet exist, and as Cartesian as the mind body connection is, I’ve always seen myself as being more than a bodysuit of flesh, blood, and bone in a bed, despite my anthropomorphic outer shell.

*

Hospital time exists in a liminal space, and I would sit in my hospital bed with a notebook, pencil, and if I was lucky, the matron’s typewriter. Over the years, I assembled the skeleton of my Bildungsroman, only to pick it apart bone by bone when I realised that hope was a lie.

*

Hospital is an unruly symphony with its alarms, beeping monitors, oximeters and IV pumps. Then there is the pulse of the hospital you can only hear when you’re submerged in the full thrall of night; the whirr-squish of rollers that trickle intravenous antibiotics into my blood, the billowing of sheets as bedlinen is changed, and the squelch of footfalls on linoleum.

When I was a child, it was common to be shocked awake with a tourniquet around my arm as a doctor pushed needles into obstinate veins. My body never belonged to me, and I tried subverting the narrative – that I had a future, even if the trajectory of my dis-ease dictated otherwise. Hope became a function of struggle and rebellion, and as I careened into the undertow of time, pulling on these delicate narrative threads became the antidote to my despair.
The ward (as memento mori)

When I am three years old, a little girl dies in the bed beside me. It is not me who remembers this, but my mother. She tells me that in the room where the little girl dies, there are six beds butted up against anaemic grey-green walls. With the curtains drawn around her bed, the other children and I play, eat our meals, receive visitors, and scream for our mothers.

Being born with an incurable lung dis-ease in the 1970s is a death sentence, and the six bed cubicle a holding bay for death – maybe even for God. Tubes of fluorescent light hum above my body, and it’s only at night that hypertonic coils of fear unfurl.

My bed is the locus of hospital life, and I bring in my own pillow and blanket to lend some warmth to the sterile hospital aesthetic. I have a core memory of my friends and I being ordered onto our beds when another child died; the curtains snapped shut so we couldn’t see wardsmen ferrying their bodies away to the morgue—as if spiriting them away would render the slate clean. The battle for erasure aside, as I loped towards adolescence these memories resurfaced like a bellyful of biting puppies, and I realised how perverse this was for a child. Absurd, even. Being displaced in my body means there are messy shards of memory, many without defined borders.

When I am fifteen, my lungs colonise a highly contagious superbug and I am shipped off to the infectious diseases ward with its air-locked single rooms. This diversion offers a singular redemptive arc, in that I have a room to myself which lends itself to adolescent debauchery. But with this new freedom comes compromise, altering the landscape from one that is collective to one that is insular and dystopian. When I can’t connect with my CF kith and kin, I become firmly yoked to my writing practice.

When I move to the adults hospital, I favour drawing the curtains around my bed in the naïve assumption that by creating a chrysalis type structure, I could keep the beeping monitors, and the men emptying their bladders into bottles – and occasionally onto my bed – at bay.

The dying room and death bed (as place and ending)

When I am 21 and on the list for a double lung transplant, the aperture of my world shrinks. Transplant time is dead time. At first, I have enough vim to wander the hospital grounds, then I become too sick to walk without being tethered to oxygen like an astronaut on a spacewalk. Like my lungs, my sense of place withers – from the ward to my hospital room, and in my last few weeks of life, to my hospital bed where my body is on full display as specimen.

There are quivers of recognition – of all the little deaths that are taking place within my body. My breasts have shrunk, and instead of looking like geological formations, my nipples are pink pearls sitting atop flat buds of breast tissue. It is like a de-pubescence, a de-blooming in a sea of linoleum, colourless, greyscale walls, and an assault of stainless steel. Then there are the more complete losses, like my mobility. With death crawling into my body, I am trapped, rendering me a silent
passenger. With barely enough energy to sit up, I can no longer read or write due to my oxygen saturations being perilously low, which turns my lips an odd shade of lilac.

*

The strangest hospital bed I’ve written in is the Intensive Care Unit. One day, as I’m waiting to have an intravenous line tunnelled into my jugular, I fish my notebook out of my bag and begin writing. ICU nurses aren’t used to their patients being conscious, much less scribbling in a notebook, but it redirects the tension from what is about to be done to my body.

There is a specific set of detritus unique to a CF bed – oxygen tubing, sputum cups, nebulisers, kidney dishes, errant plugs of mucous accidentally expectorated from lungs, gloves, empty syringes, trays of untouched food, alcohol swabs, alcohol. There is an unsettling sense of passivity being bed bound, yet it’s the only place I feel a sense of control. Before I am too sick, I can still fuck my partner – the closed door of the bathroom allowing a degree of sexual freedom. More than this, I derive a joyful kind of deviance knowing I’m having pre-marital sex in a Catholic hospital. For so long, my dis-ease has owned and inhabited me. My body is not my own, and always seems to be on loan, but with my legs embowered around my lovers head, my body is mine again. The story of my body is one that has been largely prescribed – people telling me how my body should or should not look. It was a value I was compelled to live with the moment I exploded out of my mother’s birth canal.

As a teenager there was a pervasive, internalised narrative about thin-ness, being tanned, being clear skinned. My chest is a constellation of pock marks from lines that have been indelicately threaded through my skin to give me life-preserving antibiotics. There are keloid scars that sit like pale pink badges on both sides of my upper chest, but my favourite scar is the one that looks like an abalone shell that’s been prised open with a butter knife. While the suture marks are vestigial, what can’t be seen is the metal that holds my previously crumbling sternum together that is suggestive of a hastily bent back together paper clip.

*

The hospital bed is a universal symbol of illness, but while the word ‘bed’ denotes sleep or rest, hospital is not a place for either. Hospitals are not healing places. When you’re a patient, there is a degree of involuntary submission and apathy. Being confined in one place is a rupture in the fabric of ‘lived’ time, and now, if I spend more than one night in hospital, I feel like I am in a holding pen before slaughter.

The sterility of being bed bound disseminates the space into a living mausoleum of sickness and death, of which I am an active part, but I reclaim this space by exploiting small snatches of time to write. My writing practice is an act of survival and resistance to the clichéd tropes of illness, death, and the loss of autonomy when I have no other choice but to surrender to my illness. Living systems adapt by transforming themselves, and I have learned to enflesh a fusion of adaptation and pragmatism.
The night of my transplant, my room is dismantled; my belongings gathered up and dumped into giant brown paper bags for my family to disassemble whether I live or die. When I leave, the room looks like no one has ever been there.

**The post-transplant hospital bed (as rebirth)**

My life has enjoyed a liminality of place, pinballing between home and hospital. While having a transplant pulls me out of a death grip, it never sublates other diagnoses like blood clots, cancer, diabetes, or septicaemia. Admissions to hospital are a monotony of waiting for IV infusions, blood tests, x-rays, medication, and invasive procedures in the oppressive stillness of air-locked hospital rooms.

Medicine might exist to save us, but it does not heal us, and being able to create art in an institutionalised setting has allowed a level of resistance to confinement. By forging that missing link of agency, I’ve been able to bring order in place of what often feels like abject disorder and compliance. For me, writing is the refusal to be punitively silenced – instead immersing myself in other worlds which have been the most proximal ‘thing’ to a panacea for my suffering.

We wait. We endure. We suffer. If we’re lucky, we survive and are reborn into bodies where we are strangers in yet another fractured place.

**References**
