

*What am I here for?*

Leaving Mparntwe Alice Springs by air always feels otherworldly, like the bubble of a small place bursts at takeoff, and I see from above just how far removed I've been from everyone and everything else. Each time I fly home to the East Coast – if home is where you spent most of your life – it's for reasons I don't want to return: a funeral, a breakdown, a breakup. This time it's to find my mother, not for the first time, bedridden. She's laid here for days with the blinds shut, the air around her hot and stale. When I turn the light on, it burns her eyes but more so her mind. 'Hi honey,' she says, with both softness and shame. I kiss her on the forehead. Just yesterday she cried on the phone and said 'I just don't feel myself' and I knew, like I've always known, as if her pain is carried in the depths of my own bones, that she was – in fact – not herself.

Mum's one of almost half Australians who've experienced a mental health disorder in their lifetime. Of these people, less than half of them will access treatment, which is 50 per cent less than those who seek treatment for physical suffering (Black Dog Institute, 2020). The last time she was unwell, she only received the treatment she needed when her mind shut her body down long enough for blood to collect as thick, painful clots. She was taken to ED by ambulance and once the physical was treated, she was transferred to the mental health ward with 'psychomotor retardation' and interchangeable diagnosis of bipolar and schizophrenia.

She smells like Sunday mornings. Like everything left over, or things you'd prefer to forget. She smells like mistakes made, like too many cigarettes; like bar floors stuck to the soles of your shoes. Thighs: *bones*. Forearms: *bones*. Hips: *bones*. Skin falls heavy. She looks older and younger all at once. Dad leans in to kiss her on the forehead and almost retracts – the smell. *On your wedding day you stitched two single beds together with fishing line just to lay*

*side by side*. She looks at me and says ‘You’re here to kill me, aren’t you?’ Nothing left here is recognisable.

Turning the light back off, I lay next to her on the bed, not saying anything for a while. Then this time I ask her if she trusts me and she says yes. I hold her hand and in between breaths she says ‘but not the others.’ I’m both relieved she trusts me and burdened that I’m the only one she does. She’s off her meds and is convinced that everyone around her has an agenda, conspiring together to end her life. I lay there in this lightless room and imagine my body going inside a CT machine. On the scan it reveals how much fuel inside me I’ve got to give. Right now, it’s almost 100 per cent, but I’ve just arrived. I feel guilty for thinking about myself but I’ve been here before and I know the true cost of caring.

A report published by the Workplace Gender Equality Agency, estimates that women spend 64.4 per cent of their total working week in an unpaid caring capacity (2020). This includes duties of providing physical and emotional support and assistance to others, usually family or friends – as well as contributing to the care and wellbeing of people with a disability, the frail aged, and those with a mental health or chronic condition. The labour also includes domestic work and ‘household production’ – not to be confused with the idea of leisure, for this is work some can afford the luxury to pay others to do. Unpaid caregiving is Australia’s largest industry. If we were to purchase the unpaid work – preformed predominately by women in primary caregiving roles at a rate 70 per cent – it would equate for half of the Gross Domestic Product at a total of 77.9 billion dollars annually. Despite this, unpaid care remains absent from equations of the GDP (Carers Australia, 2020). In 2020, the estimated foregone earnings for Australian carers was a total of \$15.2 billion dollars. In the case of raising children, economists believe women lose at least 17 per cent of their lifetime wages, many of

whom move into ‘mother-friendly’ occupations which are lower paid than their pre-birth positions and do not reflect a woman’s human capital: her abilities, education or work experience. Perhaps it’s simple for some to draw the conclusion that this is a woman’s choice, particularly in the area of raising children; but no mother, daughter, friend, or partner signs up for details and demands of these roles per se – there’s no contract, no tangible end, no reimbursement, and often, very little credit. The idea of credit seems foreign and so far away when the mere recognition of this role as labour is largely absent.

When my brothers are first assessed for the National Disability Insurance Scheme (NDIS) – both suffering from mental health conditions and drug abuse – my mother is incorporated into their plans as their primary caregiver. During her most recent breakdown, my brother’s services are tripled to meet the duties normally performed by my mother, taking thousands of dollars from their plans that she’d otherwise compensate. When my mum’s sick, I ask one of my brothers to do the dishes. He throws a spoon into the sink and says ‘That’s a fucking slut’s job!’ It is the very notion of gendered-roles and stereotypes of what a woman is, of what she ought to be providing, that underpins the fundamentals of the *power over* mentality that permeates abuse and violence in this nation – the grandiose delusion that something is owed to men, that they are above nature, not part of it.

When I’m with mum and no one else is around, which is almost all of the time in these early days of coming home, she screams in pain with every movement. It’s hard to discern the physical from the mental, but both are clearly suffering. She tells me someone’s trying to kill her. She says she cannot walk. I am her legs and she is heavy. After hours of trying to get her up to go to the toilet, I explain to her that I have to call the ambulance. When two men arrive, they say they’ve driven from Macksville, 55km South. They ask mum what’s wrong and she minimizes the severity, as she’s always done, saying she’s just in a ‘little pain’. One

ambulance driver looks annoyed when mum says she doesn't want to go to the hospital and he leaves the room. The other says 'well we can't force you to go anywhere, darlin.' But I want them to force her. I want them to carry her to safety. I want them to see it's almost impossible for me to manage this, alone. They tell her to take some Panadol and leave. Her limp legs look detached from the rest of her body and hang over the side of the bed. I try to gently align her legs with the rest of her body and she screams. She howls like a dog on a chain who hasn't been touched in years. I hold water and a straw up to her dry mouth and say things like 'please, one more sip.' I set my alarm for 1am, 2am, 3am – hourly intervals to wake and check her pulse. I lay back down on the hard-wired single mattress in the smallest room in the house and see myself back inside the MRI machine, vital energy sucked from my core.

The next day I wake with the sun pushing through clouds, it's humid and unlike the air of the desert. My father's in Melbourne packing up the house of his dead brother, and while my own brother is here in a way, pacing in and out the door in a daze, searching for cigarettes and things to latch onto, I feel entirely alone. I sit on the side of my mum's bed and plea with her to go to the hospital. I tell that I'll take her in, that I won't leave her, that she won't be in for months like last time. Getting her down the stairs takes a tremendous amount of coordination and effort. My brother and I stand on either side of her while she slowly makes it down the stairs and to the garage, crying out with each painful step. My brother giggles, although nothing's funny, it's just what he does. In a way, it breaks my heart to see him care for his mother in this basic, simple way when he can barely care for himself. Then I remember all the other days. In the triage room, mum looks at me, confused, and asks 'what am I here for?'

It has always seemed to me that the quality of care you receive, both from the health system and those around you, is very much dependent on the language you use and how well you can articulate, point to, and explain what's going on for you. Just a few years ago, at this same hospital, a 42-year-old man self-presented for mental health issues and concerns over his drug use – he was sent home with a Valium. He returned the next day and allegedly exaggerated a story, claiming to have a violent criminal past, which meant he could be a danger to others and was sectioned under the Mental Health Act (2007). His mother later said he made this up 'so they would admit him so he could get the help he was screaming out to get.' After waiting hours for treatment as staff questioned the lawfulness of his admission, Mr Byrne was transferred to the mental health unit, and without being searched and no substance history collected, was found dead in his room the following day. An autopsy indicated he died from multiple toxicity, a mix of drugs he had prior to entering the hospital and those he received in care. He did not receive standard observation checks, blood tests, or examination of drugs in his system.

When mum presents in hospital, she complains of back pain and very little else. Previous discharge notes from her treating psychiatrist read: 'her illness is perpetuated by her stigmatized view of mental illness, on a number of times she labelled her son's mental illness (both are diagnosed with schizophrenia) as similar to her illness, but didn't want to name it.' Shame: it thrives in silence. I look at mum and apologise for talking for her, then tell the nurse that yes, she's in bad physical pain and can barely walk; but that she got this way after coming off her antipsychotics and spending days, if not weeks, in bed. The nurse takes mum and I to a waiting room and mum looks at me in fear. Later she takes small bites of a cheese sandwich and mumbles 'gas chamber'. At every point, I have to try and preempt mums' thoughts and feelings in order to reduce the darkness of them. When a nurse starts to wheel

her away without saying anything, mum looks back at me in a panic. I ask each health worker to please clearly explain what's happening, where they are taking her, as she silently fears they will kill her. She's moved to an old ward while the hospital is undergoing upgrades. The doctor tells mum she has a severe UTI and five bags of fluids drip through her veins slowly. She's started to take her antipsychotics again, but her mind is incredibly fragile. I text a friend and say, 'I'm not sure what to do next.' He replies, 'You have a home now, take her there.'

Sometimes, when my mind entertains the scenarios it spins, I'd see myself at my mum's funeral. I'd be driving along the highway or flying through the sky and then in my mind I'm standing behind the pew, trying to put together some rambling eulogy. The problem I face is that these final words are always so exterior, as if the aim of this last goodbye is to get the members in the audience to nod along in recognition, to think yes, that's true of the woman I knew. But for mum, and many women, these people here know very little. The brothers, the sons – all they see is what they lose, not what she's lost. I can't simply say 'what a generous woman she was,' because her generosity is intrinsically, delicately interwoven with the expectation of labour, of motherhood, of survival. I know already that there's a certain type of sadness that comes with the impossibility of peace. How can I accept the ending when the life lived feels robbed, stripped of dreams and energy by the hands of others? I'm angry up here, on this stand and in my mind, in front of all these fools and familiar faces, who wipe tears before they fall with handkerchiefs she probably washed for them.

After three connecting flights and fourteen hours in transit, we arrive in the red, pulsing heartland of the country. Mum slowly unpacks the small amount of belongings she has on one side of the bed as if they're all foreign to her and says things like, 'I don't want to be a

burden, honey'. I kiss her on the forehead and tell her, for the first of so many times, that she is anything but a burden. For many people it seems there's something incredibly healing about Mparntwe Alice Springs. Friends drop by with homemade meals for mum, others take her to the galleries and gardens when I'm at work. When I'm not at work, mum is with me all of the time. She's unable to be left for long periods and although the only alone time I get is while I'm sleeping, it's incredibly isolating to care for someone in this way. It's the generosity of those around me in this community who keep me afloat when I sink into the often-solitary depths of caring. I slipped almost seamlessly from being a daughter to being a carer – although never really saw myself as one. I come to believe that you cannot do this alone – that it's impossible to maintain all elements of your own life and someone else's – but yet, currently 3.5 per cent of the country do just that (ABS, 2019).

It's kind of ironic in a way that one of the things that helped my mum heal in those weeks of being in the desert was being immersed in water at the town pool. The pool is a space in this often-divided town that feels like an equal space for everyone. A town where Indigenous kids can't go to the library unattended by an adult, where shops hang signs that say "no school, no service." Here though, everyone's floating and diving and the place smells like free BBQ and chlorine. Mum comes to the pool three times a week for water aerobics. On Mondays, I join her, and on the other days, an old boss of mine takes her to move and stretch underneath the water's surface. At times, it's a battle to convince her of the value of showing up for the class. She's happy there's social distancing in the water as she's still paranoid about the people around her. By the second week, though, this becomes her happy place. Most of these people here, a majority of them women, are in their 60s or 70s and come for social connection as much as exercise. Teacher's play old school tunes and instruct with enthusiasm and there's a rare beauty in the collective synchronicity of aging bones dancing under the

water. Some days, I hang off mum's back like the little kids do and she laughs and spins me around. I tell her the extra weight is good for her, but really, I just revel in the feeling of switching back roles, of being the child whose mum can carry her for one brief, weightless moment.

We meet with a locum psychiatrist from the Crises Assessment Triage Team (CATT) twice a week in the middle of my working days. He adjusts his suspenders, leans forward and says “I am going to tell you the same thing each time you come here: you could have died.” Mum says nothing, he leans further in and says “I want you to understand that the psychosis you were in could have been much, much worse – had someone not intervened, we might not be here today.’ Mum nods her head and tries to swallow this thought. When we leave each time, she cries the whole drive home.

My own fear was never of dying; of snake bites or public speaking; of earthquakes erupting or darkness or blood; it was of being ‘mad’. A woman in a white gown, a woman having lost control, a woman whose identity had been stripped because she was now not a mother, now incapable of mothering, as if that’s all she ever was. My greatest fear was to be my mother when she’d lost her mind, when agency dripped from her, was poked out of her, prodded, shocked. Whenever my mind spiraled, whenever I pushed the boundaries for too long, left broken and embodying shame on a random Tuesday, I saw myself being wheeled in, being stripped, being dressed in a cheap cotton gown with ass-cheeks exposed at the back, sticking to the leather of thin beds and sunken chairs; forking mashed potato, spinning useless clay, floating in a sea of the unwell. My fear, I think, was ultimately to be perceived as only the actions of thankless labour, laying on the hospital bed thinking *who am I?* If I’m not



preparing dinner for others, *is there any point in eating?* If no one notices the changes in my skin, *are the cracks really there?* If I'm not folding tea towels, *then what am I here for?*

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