Chapter 9.

Altered Spaces, Relationships and Identities: Supporting people experiencing mental distress in the home

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Biography:

Dr Caroline Lambert was told by her Grade 5 teacher that her "happy-go-lucky nature would eventually get her into hot water". Whether that is the case is yet to be determined. Caroline often uses her lived experiences to inform her research and writing. She is a senior academic at RMIT University, Australia.

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Biography:

Amaya Alvarez is an ocean brained researcher of Basque Welsh heritage. She draws on her lived experience to inform her practice in policy and advocacy and research. But has timeout imagining herself in other landscapes with friendly wombats, otters and beavers. She is a family carer researcher at RMIT University and works as a lived experience researcher for a large mental health community organisation Mind Australia.

Abstract

In this provocation, the authors draw on feminist scholarship, the collective knowledge of families and carers in their communities, as well as their own lived and living experience of supporting people experiencing psychological or mental distress, to proffer the notion that our homes hold and represent the score of all emotions experienced within the materiality of our primary dwelling. There are three underpinning conjectures; firstly, that having shelter has become a privilege that a growing number of people have no access to; secondly, that the concept of home as a beneficial or positive space is actually a gendered notion; and thirdly, that the identity of home is fluid as the materiality will always change according to environment, age, wear and use. The authors conclude by inviting readers to imagine a version of *Homefullness* that is elastic enough to embrace and celebrate the messy and complex versions of ourselves.

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Introduction

Just as some trauma experts suggest that the human body holds the score for trauma experienced (Van de Kolk, 2014), the authors of this provocation suggest that the home also holds the score for many families and carers of people experiencing psychological or mental distress. Our contention is an extension of Edward Casey's notion that the materiality of home is an addendum, or mirror of the bodies that inhabit the dwelling (Young, 1997; Young, 2005). For example, the dent in the skirting board of a bedroom serves as a reminder of the time a canister or cylinder vacuum machine was recklessly pulled along by an older woman, furious at having seemingly endless housekeeping duties pile up in a house full of physically capable young men. More literally, the names of children are etched into the wall of the kitchen pantry, with lines and dates to record their growth over decades. Each time we notice the dents, lines or dates; we may feel a range of emotions. The walls and physical structures that make up our home can store and visually represent all the emotions, joys, losses and sadnesses that are experienced by those living their lives within a home.

Thus there are three underpinning conjectures within this chapter. The first is that having shelter – a home if you will – has become a privilege that a growing number of people have no access to. The second conjecture is that the concept of home as a beneficial or positive space for those who reside within, is actually a gendered notion, strongly substantiated by statistics of family violence. The third conjecture is that the home is fluid, it contains no fixed identity in that the material of a home will always change according to environment, age, wear or use.

In this chapter, as family members or carers of people experiencing mental health distress, we share and reflect on the embodied experience of the *home, of place* – and of *Homefullness*. We have created images that represent a deep connection to embodied experience, doing so in order to help imagine and explore how feelings about the everyday spaces of home can shift dramatically when the home becomes a site of State and system-endorsed caring.

But first an orientation. What is a mental health carer? Within the Australian context, the terms ‘families or carers’ are often used to refer to people who, in an unpaid capacity, support someone experiencing mental distress. Often this support is provided through sharing of housing, financial or practical resources and/or providing psychological, emotional, and spiritual support. While carers may be familial, for all

carers, their connection to the person they support is relational. In Australia, carers or the concept of 'the carer', is often a construction of public policy and legislation, and is considered a critical dimension of the mental health system. Why are carers identified as such? We know that, in the wake of deinstitutionalisation, the dominance of the medical model in conceptualising and treating mental distress, and the rise of neoliberal governance has led to a lack of safe, accessible, compassionate mental health community supports. This, in turn, has seen the parallel emergence of the category 'carer' as a socio-political and bureaucratised identity (Zhang, 2023). As carers we are often charged with the responsibility for doing the work the system fails to (Katterl et al., 2023). This systemic positioning has led families and carers, people like us, to inhabit spaces often experienced as precarious and unsafe, isolated, and confined. As we discussed previously these are spaces which embody memories, sometimes of trauma, loss and grief.

Added to this over-responsibilisation, research also documents that the role of the carer is highly gendered. As many scholars have argued, care is a feminist concern (Brannelly & Barnes, 2022; Featherstone & Morris, 2012; Klostermann et al., 2022). These scholars provide insight into the socio-economic and cultural dimensions of the gendered nature of unpaid care and argue for change in distribution; recognition of value and greater share of care across the community (Chang, 2020; Graham, 2022). Data supports this, indicating that actively supporting people with psychological distress in an informal and unpaid capacity is highly gendered, with conservative estimates indicating that in Australia, around 70% of all family carers are woman (Deloitte Access Economics, 2022).

Through a photographic and textual account, the authors – who identify as women, and as lived experience scholars – will explore how the experience of being carers changes their relationship and sense of home, as their identity, relationships and their home spaces are altered to fit the immediate and ongoing demands of the system and the needs of the person or peoples they support. The text will be framed by the wisdoms of feminist scholars such as Iris Marion Young and Allison Weir, who recognise that home and relational identities are critical values that should be accessible to all (Cin et al., 2025; Davis, 2021; McDowell, 2003).

We invite the reader to view the provided photographs through our shared lens. But first a couple of notes on language and intersectionality before we proceed. When we speak of family, we understand family in a broad, generous, and contextual sense – of birth or adoption, blood or choice, of circumstance, kinship, of foster care, friendship, or identity. We note that experiences of mental distress sometimes intersect with alcohol and other drugs dependency, and further, recognise that the impact of such intersections is often

born harder by those with additional marginalised identities and experiences, or with fewer privileges to help moderate the experience of oppression and suffering. Further, we want to emphasise that many carers support more than one person and also have experience of their own mental health challenges and mental illness (Carers Australia, 2018; McAuliffe et al., 2009).

Whilst using the term 'carer' we also seek to highlight the problematic construction of the carer identity or 'carer relationship' and note that we feel deep ambivalence to the label, and the way in which it is exploited by the health system and the State. Through our own experiences, and in holding the voices of others, we speak to the violence of the State, in its overreach and underreach of families and carers supporting people experiencing mental distress. We speak of the harms to our ordinary lives, and the spaces we occupy as home. We also seek to illuminate that the home can be both a site for dignity and hope, and of resistance and activism.

Construction of care

So much of the public narrative on unpaid care – or on 'being a carer' – focuses on the transactional; what we do, how we do it or how we may be tasked to do it. More often than not our work is framed as a series of tasks or as categories of labour such as *physical care*; showering, cooking, washing, shopping, medication and so on, and *emotional or spiritual care*; coaching, encouraging, distracting and engaging. As carers we are prescribed or tasked with fulfilling a 'role' through this work (Rowe, 2012). We are charged with the responsibility for it, often unwittingly, and often when we may not be well equipped for it, because we can't afford to take time off work, or we have our own health needs, or have multiple care responsibilities. We are made to feel if we do not carry out this critical work we are not 'caring' enough, or responsible enough as parent, partner, sibling, friend. *We* are never enough. The role exists as though the relational, contextual, and spatial dimensions of care are simply a list of chores. These lists flatten out or disguise our true experiences. These lists negate the embodied nature of care (Hamington, 2004), the messiness, the complexity, the ambivalence, and the 'pasado' (Mendez-Luck et al., 2019). There is so much that is not accounted for in government policy or legislative responses. These omissions are of course by design. For people providing support in the mental health space this omission is particularly impactful, given that across the world, the mental health system often comes second or third to other health funding priorities and is left off much of the discourse of caring itself (Mahomed, 2020). The construction of the mental health carer identity and role is often steeped in pathologisation, discrimination and blame. Julia Twigg in her seminal book on the emergence of the 'carer' articulates this with clarity:

> …. mental health carers are invisible and often not included in discussions of caring because what they do and how they are responding is poorly understood. Mental illness isn't visible in the way that physical disability often is … mental illness is often hidden within families due to stigma and shame. Families are often blamed, judged, or seen as part of the problem, whereas other carers are seen as part of the solution. (Twigg & Atkin, 1994, p. 106)

Of course, when caring for someone engaged with mental health services intersects with other sectors such as the correctional, addiction services or forensic systems, then the discriminatory and stigmatising positioning of carers only increases (Chemerynska et al., 2020).

As much of the research on carers attests, being deployed as a carer saves the State and the community money (Diminic et al., 2017), however the authors argue that the true cost of positioning carers as 'the backbone of the economy' (Australian Government, 2023a, p. 4) *sounds* more like exploitation, and *feels* like lost opportunities for meaningful community connection, flourishing interpersonal relationships or meaningful educative and employment opportunities. This construction of the carer role can – in reality – *look* like compromised physical health, mental distress, trauma responses, or underemployment or insecure housing. The affective impacts of such carer exploitation can manifest in the physical spaces we inhabit, with stress, anger, shame, uncertainty, and fear permeating our built material spaces. The well-established design concept and practice of Trauma Informed Design (TID), recognises that healing can occur through paying heed to our senses, psychology and natural elements in the planning and design of spaces we inhabit (Ames & Loebach, 2023). Conversely, the authors suggest that when our dwellings have held the big feelings, painful experiences and hard memories of its occupants, the score that the space holds – no matter how trauma-informed the design – can perpetuate harm to those within. While TID is often considered and funded within the domain of public institutions, it is service users' families and carers who are tasked with tending to the home in which a service user will mostly live. It is for the families, the carers, and kin for whom this chapter is written.

Understanding the shifting experience of home as embodied

… I get my house keys out, but the front door is unlocked. I breathe deeply, bracing myself to cross the threshold. I am met with silence. But a silence resonant with possibilities.

A heavy silence.

I call out 'I'm home.' But am met with the heaviness of silence. The space feels both empty and constricting. Walking tentatively down the hall I scan the rooms I pass. Empty. Empty. Then a closed door. 'Hey,' I call more softly 'are you OK?' The silence stretches.

Maybe they have headphones on. Maybe they have had a good day and are scrolling online. Maybe they are sleeping, the fitful sleep of the mentally exhausted. Maybe … maybe.

Or maybe they are there but they cannot speak. Maybe … my body shifts to high alert. The walls hold the emotions of previous crises. The closed door not simply a door marking boundaries of privacy, but a barrier to connection. A border between the familiar and a landscape that is strange and internal and unknowable.

The quiet is not welcoming. It is accusing and heavy.

Why did I go out?

My system flooded with the adrenaline of past experiences. 'Why did I leave them? I didn't need to go out. I am such an idiot. So selfish. What was I thinking …' Determinedly my hand closes on the door handle – I push it open …

We invite others to imagine our experiences. We share this vignette, a hybrid of our own realities, because we are invested in finding ways that capture how our experiences of the home are changed by the positioning of us by others. Our photographs provide a visual language that powerfully reflects the lived experience realities of what happens when distress is an everyday occurrence. They speak to how home changes when the expectations of our capacity to manage, and enable recovery or healing create significant physical, relational and emotional ruptures or harms in the spaces.

In feminist scholarship home has always been explored in critical ways, Tanner in her examination of the fictional work of Marilynn Robinson described it thus: '"Home" unsettles the culturally sanctioned idea of home as an escape from the contesting ideologies of the larger world' (Tanner, 2021, p. 91). In her analysis of Robinson's fiction, Tanner highlights how home is not always a stable refuge from the world, but rather their exploration reflects, reinforces and amplifies the experience for families navigating the

responsibilities and complexity of mental health. The intrusion of powerful ideologies of care and gender, individualism and work, intensify and constrain the relational experiences and make life harder for carers (Young, 2005).

Feminist geographers also offer work that explores the idea of home as an embodied space. Sophie Bowlby for instance (2012) develops the concept of 'caringscapes' to describe the spatial and temporal dimensions of informal care arrangements. Blunt, in her analysis (2005), argues for a turn to the spatial dimensions of home as a place of care, contributing a great deal towards a fuller understanding of home by using the term 'therapeutic landscapes' to describe the way home is constructed as a place to recover or get well. This is a construction that resonates with the authors' own lived experiences and has synergy with the concept and practice of TID.

With the current shift in health care translating into increased demands being placed upon informal caregivers in the home, a new understanding of home-place, both in meaning and place-identity, must be sought out. As Weir (2009) argues, our understanding of home should not be reduced simply to binary of 'good' or 'bad'; an instrument of oppression, or a site of comfort and unity; rather, for many carers, home can be experienced as a complex entanglement of sanctuary *and* trauma, love *and* loss, entrapment *and* hope. In this entanglement, it is the aspiration of something better for family carers, and for those they support, that makes the privilege of 'home' worth fighting for.

The intention of the following provocations are to honour the experiences of carers who have had their identity, relationships and their home spaces altered to fit the immediate and ongoing needs of the person they support, often due in part to the exhortation and demands of the State to do so in ways that can create a kind of violence and disruption that injures all within this relational, messy space that we call 'home'.

The Dinner Table: What does the dining table represent?



<Figure 9.1. here>

Figure 9.1. The Dinner Table: what does the dining table represent? Image by Matilda Alvarez.

For the authors, the table (see Figure 9.1) is a now mocking space, capturing changed identities and fractured relationships. Once joyful, messy and noisy, the dining table has become a barometer for difficulties and irrevocably changed relationships. The relationship of the carer to this changed dining room table becomes complex, entangled, and non-dichotomous. The dining room table has sometimes been experienced by women as a symbol of oppression and servitude (Delphy, 2016), yet, it can also be experienced as a source of satisfaction or pride, and a symbol of love and care (Meah, 2014; Meah & Jackson, 2013). We felt keenly, as women, that we are often judged by our ability, or otherwise, to nourish and sustain our children, partners or other family.

Although arguably the work of providing sustenance or nourishment in the home is not always highly valued by society, for women carers, in this scenario the ‘inability’ to nourish others, the inability to

perform this ‘act of care’ feels devastating. Grief and loss are a constant reminder of failure, and re-negotiation of identity from a provider or nurturer to something other.

The table becomes a place of absence, where the familial configurations and relationships that once took place around and across the table are no longer there. This loss of these sites of everyday life are amplified through insight into the table spaces of others. Other tables, other families, other relationships seem less fraught, unknowable and unsettled.

The Dispensary: How are carers co-opted?



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Figure 9.2. The Dispensary: How are carers co-opted? Image by Matilda Alvarez.

Families and carers are at risk of State co-option when we become unwilling and unqualified pharmacists and clinicians (see Figure 9.2). Extending the clinical gaze into our homes we are charged with ensuring compliance with prescribed medication, not always understanding what they are for, how they help, or might harm, or who has prescribed them and why. We find ourselves insisting on this compliance at a cost to our relationships and our sense of knowing what might be right or just. In insisting on compliance, we are often seen as and feel aligned to the often-fraught, rights-breaching medical system, rather than allies with the person we are trying to support (Katterl et al., 2023). The bathroom and medicine cabinet becomes a place of tension and dispute, confusion and dread.

Supporting people in mental health can come with a particular set of under-recognised impacts, including relational rupture; pathologisation of family and culture; the uncertainty of diagnosis and misdiagnoses; and the lack of attention and response to intergenerational and intragenerational trauma and crisis. The experience of intense and persistent distress, and the way these can change a person from known to unknowable in a familial context, is compounded by the medical model response that favours hyper-individualised treatment over cultural, spiritual, social and relational understandings of health and mental health.

Once labelled by the State as ‘mental health carers’, we occupy a place where we are expected to work with clinicians, institutions and service providers, to ensure compliance, or ‘full’ engagement in (questionable) treatment, as well as being ‘responsibilised’ with the safety of the person that we are tasked to care for. It should go without saying that sometimes, carers are not the safest option for people who are experiencing distress. Carers often experience responsibilisation and co-option simultaneously with being accused of negating people's rights to choose, right to privacy, or of infantilizing, neglecting or controlling. The experience of supporting and of being supported, is often perplexing and messy. It rarely holds the clarity depicted in the glossy brochures of clinics and institutions, where smiling faces talk an unrecognizable and sanitised language of ‘journey,’ ‘hope’ and ‘loved ones’.

As mental health family and carers we are enrolled as essential to the success of the mental health system despite high numbers of families that are not connected to the system at all, or for whom the system has failed (Australian Government, 2023b; Gooding, 2016). In Australia, mental health families and carers are described as ‘filling the gaps in an under-resourced system’ or as the ‘third space’ of care: sitting

between hospital and clinical services, and the under-resourced community health sector. In this context our homes become – and are constructed as – sites of support, of care in an operationalised and transactional way, with little consideration of how reasonable these responsibilities are, how limited in their understanding of family they might be (white, heteronormative and middle class) and how they further weaponise the State against women in diverse communities and those living precarious lives.

The Third Drawer Down: A home should never be free of risk



<Figure 9.3. here>

Figure 9.3. The Third Drawer Down: a home should never be free of risk, Image by Matilda Alvarez.

In the context of risk, distress and harm, both authors have, at times, been asked to maintain suicide-watch, to stay vigilant for signs of self-harming behaviors. This request is not uncommon for 'mental

health carers' and is one which tars us in clinical language and sells us a lie that diminished choice and deprivation is the key to suicide prevention, and that suicide and self-harm risk assessments work in forecasting outcomes, that they are based on solid science, and immutable evidence. Feasting on our desperation, the state vigilance invades our homes, creeping into the kitchen drawer … and suddenly that drawer full of a random collection of useful bits and bobs becomes a source of risk, of harm.

String, curls of wire, matches, Stanley knife, secateurs, glue, knives, gaffer tape, batteries, boot polish, sewing needles, dental floss, pencil sharpener, packet of pins, thumb tacks ... (see Figure 9.3)

We are charged by clinical services with making our homes safe, with eliminating any object that could be used for self-harm. This drawer, this innocuous messy space, is considered filled with such dangers. The drawer becomes a metaphor for the whole house and the multiple everyday risks it contains. Cutlery is emptied into the garage or locked in a cupboard. Glasses replaced with plastic cups. These modifications are expected of us to mitigate perceived risk – such a straightforward request, isn't it? It creates a home of vigilance, of sleeplessness, of surveillance and if or when something happens – because such vigilance is impossible in the spaces of home, where there can always be something missed, or a family member bringing an object home that is so ordinary it is overlooked – there is such guilt and self-blame.

The emptying out of the home in these moments denies the unsustainability of these changes, their inadequacy in the face of distress. For how long, we ask ourselves, will the impositions they create be with us. Uncertainty sits alongside the vigilance.

***Homefullness*: A carer givers provocation**

In presenting our lived realities, we seek to share and illustrate the uncertainty and impossibility that carers often experience, not only due to our over-responsibilisation by the State, and positioning as the backbone of the care and support economy, but also because of our gender and the exploitation of our emotional and physical labor as women. This narrative is woven tightly into the fabric of neoliberal economies.

We highlight the embodied nature of these expectations, how they occur in place, changing our response to familiar spaces, their materiality and the familial impacts of our carer embodiment. In being identified

as ‘carers’ we are often tasked with ensuring ‘compliance,’ ‘safety,’ and ‘risk management’ in our homes, and in that demand, there is something of our own relational-being that is lost. When we experience and hold and try to support a person’s distress something stretches within our homes, testing all of the relationships within, often amplifying distress.

However, in describing this recalibration of our sense of ‘home’ we are not suggesting that these experiences are irrevocable or unavoidable. Families and homes can be, and are, places of healing and safety, but not when people are carrying too much, or are asked to act ‘in the interest’ of their family member, against the wishes of that person with all the subsequent tensions and self-recrimination that flow. We are not clinicians or peer workers. We have busy, complex and unruly lives. In offering these images we encourage curiosity as to how society might shift away from the exploitative positioning of those of us who try to support the distressed. How might families and carers become reimagined as someone more than a co-opted apparatus of the State, moving towards a position which is embodied, critical, and ultimately destabilising to those mental models that hold the status quo?

Feminist scholar Roberta Rubenstein writes about the emotional epistemology of domestic space. For her, ‘home’ is never ‘merely a physical structure or a geographical location but always an emotional space and as such, she argues, ‘home is among the most emotionally complex and resonant concepts in our psychic vocabulary’… (Rubenstein, 2001, p. 2). Home is, she argues, an ‘emotionally resonant topos’ (p. 3). In the work of something akin to a way forward, we hope that our provocations open up rather than close in the possibilities of challenging our carer identities, while reclaiming something of ourselves at home. We have narrated through images and experiences our family and carer ‘topos’ and, in doing so, we invite readers to imagine a version of *Homefullness* that is expansive, or elastic enough to embrace and celebrate the messy and complex versions of ourselves.

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