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**Heeding the ‘wild red flag’: Listening to stories of miscarriage to grow our capacity for  
care**

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## Abstract

While common, miscarriage can be devastating and traumatic for women, both physically and emotionally, with women experiencing notable grief and distress that is often enduring and life-changing. Care received under the medical gaze of the health system is often constrained to women's bodies and 'products of conception', disregarding and dismissing women's emotional experiences and needs, and social support is often scarce, fraught, and inadequate due to pervasive processes of silencing and stigma surrounding miscarriage. Given that social support plays a pivotal role in how miscarriage is experienced by women, the aim of this research was to better understand the complexities of social support for women who miscarry and to explore pathways for improved care. Grounded in feminist standpoint epistemology and narrative inquiry, this research sought to resist the silencing of miscarriage through privileging women's voices, experience and lives in the context of miscarriage. Through in-depth interviews, six women's stories of miscarriage and social support were analysed using The Listening Guide to identify the plot, I poems and Contrapuntal voices. An additional analytic step involved bringing the women together to 'speak' in conversation with one another, enabling an exploration of the complexity and diversity of women's experiences of support through and following miscarriage from the women's collective standpoint. Four narrative threads were woven through their stories: You're A Woman, You Have Children; No One Talks About It; We're Women, We Suffer; and Something Good At The End. These narratives spoke to, and challenged, processes of silencing, social norms and expectations of womanhood, motherhood, and 'healing', urging us to transform the ways we can talk about, understand and respond to miscarriage. Listening to the women, for real, urges us all to open spaces for diverse and complex stories of miscarriage, enabling us to grow our collective story of miscarriage in order to honour women's motherhood, their babies, and their grief, increasing our capacity for connection and care.

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## Chapter One: My/Our Stories of Miscarriage

### My Story of Miscarriage

I thought I knew miscarriage.

I thought miscarriage was rare. Now I know that one in five pregnancies end in miscarriage, and that some women, like me, miscarry multiple times.

I thought that avoiding soft cheeses and sushi would protect me from miscarriage. But I avoided soft cheeses and sushi, and my babies still died.

I thought that the second trimester of pregnancy was a safe zone. As that magical 12 week point passed I exhaled, and happily shared my news with my loved ones. But twice I miscarried in my second trimester.

I thought miscarriage was signalled to women by blood in their underwear. But for me, there was no tell-tale blood. My first miscarriage was signalled when an ultrasound technician said, *“I’m sorry, there’s no heartbeat”*. My second miscarriage was signalled when, at 19 weeks and 6 days pregnant, my midwife searched, and searched, and searched for a heartbeat at a routine appointment. After a tearful walk along a busy road to the hospital, I saw my baby floating on a sonogram. His size indicated that he had ceased living at 16 weeks’ gestation. I hadn’t known my baby could be dead inside me for four weeks.

I thought miscarriage was like a heavy period. But for me, miscarriage meant bleeding so heavily that I feared for my life. Miscarriage meant terror, as I was told to head home, but to seek medical care if I started passing “clots the size of oranges”. Terror again, mere hours later in bathroom, as clots the size of oranges fell from my body. Unlike a heavy period, miscarriage had me stumbling across a hospital car park into the emergency department wrapped in a blood-soaked towel after a frenzied drive across the city. Finding my own handprint in dried blood on the side of my car the next day.

I thought miscarriage meant there wasn't really a baby, yet. But at home in my bathroom I caught a small baby in my hand. The following year, I birthed another, bigger baby in a delivery room at the hospital. Babies that I could see and hold, babies that I buried.

I thought that after miscarriage a healthy, living baby would arrive and heal me. But my first miscarriage was followed by another miscarriage. My second miscarriage plunged my husband and I into a year of post-mortem results, genetic testing, murkiness and heartache. I ran out of steam. I felt that trying again for a baby might break me.

I thought my friendships would survive miscarriage. But in the aftermath of my losses some of my most cherished friendships broke down. An initial outpouring of care, love and support seemed to ebb away as months went by. Friends who were pregnant or trying to get pregnant retreated. *You can't understand how hard it is to be pregnant and be around someone like you*, a friend told me. *I love you very much but have to kinda focus on what's ok for me right now*, I heard. I retreated too. I was engulfed in grief, messy, desperate for support and understanding and love, and what that did was fracture some of my most vital friendships beyond repair. Loss, after loss, after loss.

I thought

*it's nature's way*

*it wasn't meant to be*

*everything happens for a reason*

*you can always try again*

*at least you weren't further along*

*at least you can get pregnant*

*at least you have another child*

*be grateful for what you have*

I thought that miscarriage would be fleeting, a brief moment of sorrow. But miscarriage has permeated my life and become an enduring negotiation of presence and absence. I have lived miscarriage with my body and my heart, and through my relationships. It has become embedded in the spaces I move through and inhabit. Miscarriage has changed me, too. It has steeled me and it has softened me. It has birthed distrust of my body, existential worry, wariness in friendships and newfound intimacy with anxiety. It has also opened spaces for new relationships and connections that are nourishing and feel safe.

I come to this research with my own story of miscarriage. A story that is at odds from the story of miscarriage I once knew. I have learned that there is not a single story of miscarriage but many, a great number of which are unspoken and unheard. We cannot begin to truly know miscarriage until we start to listen, closely, to those who have lived it. And through this research, my hope is that through stories and voice, together we will begin a more expansive story of miscarriage. The voices that tell this story are multiple: voices from academia, the voices of six women who have participated in this research, and my own voice. Together these voices will reject the silence and address the misconceptions that surround miscarriage, and together these voices will narrate a collective story that can open spaces to learn how to better support women in the wake of miscarriage.

### **The (un)Common Story of Miscarriage**

I am not alone in my story of journeying through the grief of losing a baby; many women hold a story of miscarriage. One in ten women will experience miscarriage in their lifetime (The Lancet, 2021) with approximately one in five pregnancies ending in miscarriage (McCarthy et al., 2020), the vast majority of which occur during the first trimester of pregnancy (Ross, 2015). In Aotearoa New Zealand an estimated 25,000 miscarriages occur annually (Yang et al., 2022). Precise determination of the prevalence of miscarriage proves difficult, however, as estimations tend to reflect clinically recognised miscarriages, neglecting

to account for miscarriages that occur when women are unaware that they are pregnant or when they do not seek medical care (Strumpf et al., 2021). Furthermore, determining how frequently miscarriage occurs is complicated as definitions of miscarriage vary considerably across geographic regions and institutions (Quenby et al., 2021). Broadly, miscarriage can be defined as the loss of a pregnancy before foetal viability, or the point at which a baby can likely survive outside a woman's body. As variations in viability based on gestational length vary, ranging from 20 to 28 weeks of pregnancy, so too do conceptualisations of miscarriage (Quenby et al., 2021). In Aotearoa New Zealand miscarriage is legally determined to be the death of a baby before the 21<sup>st</sup> week of pregnancy; the death of a baby later in pregnancy is deemed a stillbirth (Births, Deaths, Marriages, and Relationships Registration Act, 2021).

For women, miscarriage can be a harrowing experience both physically and emotionally. To lose a baby during pregnancy can be traumatic (Engelhard, 2004; Lee & Slade, 1996) and can generate profound and heart-wrenching grief (Brier, 2008; Flach et al., 2022; Janssen et al., 1997). Alongside grief, women report feelings of isolation, fear, helplessness, guilt, self-blame, loneliness, deprivation, overwhelm and insecurity (Abboud & Liamputtong, 2002; Adolfsson et al., 2004; Bellhouse et al., 2019; Gerber-Epstein et al., 2009; Harvey et al., 2001; Maker & Ogden, 2003; Meaney et al., 2017; Swanson et al., 2007). A sizeable body of research has explored the psychiatric consequences of miscarriage for women, showing miscarriage to be associated with significant mental distress, including depression, anxiety, and posttraumatic stress (Broquet, 1999; Davoudian et al., 2021; Farren et al., 2020; Frost & Condon, 1996; Herbert et al., 2022; Lok et al., 2010; Quenby et al., 2021).

The prevalence data and psychological research findings tell me that I am not alone in my experience of miscarriage and my pain, yet as I embarked on writing an introduction that introduced 'miscarriage' for this thesis, I found myself struggling to find the shared embodied

and emotional experience through the clinical and categorial terminology that dominated descriptions of miscarriage. Many of the terms have been troubling, affronting and discordant with my own experiences. For instance, in Aotearoa New Zealand, miscarriage is legally defined as “the issue from its mother, before the 21<sup>st</sup> week of pregnancy, of a dead foetus weighing less than 400g” (Births, Deaths, Marriages, and Relationships Registration Act, 2021), reducing my experience to medical events and processes that obscure the existence of the baby that lived, and mattered, to its mother. Furthermore, consideration of gestational thresholds works to categorise baby loss in a way that label one woman’s loss a miscarriage (before the 21<sup>st</sup> week of pregnancy) and another woman’s loss a stillbirth (after the 20<sup>th</sup> week of pregnancy), and assigns the gravity of that loss by those terms. By law a stillborn baby’s birth must be registered, their body cremated or buried, and bereaved parents may order a birth certificate, if they wish (Burial and Cremation Act, 1964). The same is not true for miscarriage, with no guidelines for how to handle a baby’s body, and no possibility for a birth or death certificate to recognise the baby’s life, and death. Engaging with the literature, it became clear to me that how we understand and make sense of miscarriage is dominated by highly clinical and medical language, and, therefore, to begin to ‘know’ miscarriage, a further exploration of the medicalisation of miscarriage is needed.

### ***Women’s Bodies Under the Medical Gaze***

In modern society, pregnancy and miscarriage are often situated within the realm of medicine. The increasing authority of the medical institution and of medical professions over reproduction has seen a movement from the knowledge and practices of pregnancy and birth falling under the domain of midwifery and women’s own embodied knowledges, to being decisively medicalised, where the medical institution is seen as the best, or sometimes only, source of knowledge about reproduction (Davison, 2020; Johanson et al., 2002; Rothman, 2014). Medicalisation is the process whereby aspects of human life become vastly understood

and experienced through the discourses and practices of the medical institution (Lupton, 1997). From this perspective the body comes into focus under what Foucault (1994) referred to as the ‘medical gaze’, whereby the body is brought into a “field of visibility” (Lupton, 1997, p. 99) by medical practitioners through the activities of observation, examination and comparison. Under the medical gaze, only the body is seen, and seen only for its parts: its blood, bones, tissues, organs and biological systems. The body is separated from the ‘human being’, as the human being becomes the mere sum of its component parts, rendering the ‘human’ into biological categories for surveillance, assessment and intervention through the authority of the medical institution; an authority that disregards the embodied and affective human experience as irrelevant.

The embeddedness of miscarriage within the medical realm flows on from the medicalisation of women’s reproductive bodies more broadly. In Western society the experience of pregnancy has transformed from being a ‘natural’ state to being brought under the dominion of the medical institution (Lupton, 2012), producing what Reinharz (1988) refers to as a “natural yet medicalised” (p. 88) view of pregnancy. Under this medicalised view, the pregnant body is only ‘knowable’ through the practices of medical observation and examination by medical practitioners, “marking the pregnant woman as Other even to herself” (Cummins, 2014, p. 42) and subjugating women as ‘knowers’ of their own embodied experiences during pregnancy. Medical monitoring has become the norm for pregnancy, birth and even prior to conception as those hopeful to conceive turn to medical providers to ready their bodies for pregnancy, seeking nutrition or lifestyle advice that might increase their chances of conceiving a healthy child. For those who struggle to conceive, expert medical guidance and the advent of reproductive technologies provide the means of possibility for pregnancy and a baby their arms. The way we know pregnancy and birth is so bound with the medical institution that the notion of pregnancy or birth with no medical intervention—no

midwives or doctors, prenatal vitamins, ultrasound, blood tests, or birthing assistance—is perceived as radical, irresponsible and fringe (Feeley & Thomson, 2016).

The close surveillance of women's bodies through pregnancy, and the heavy focus on the production of a healthy baby, supports the notion that both pregnancy, and women's bodies, are risky (Ross, 2015). Routine monitoring, lifestyle directives and nutritional supplements, alongside technological interventions such as ultrasound scans, foetal heart rate monitoring and genetic screening all signal a sense of risk, particularly in early pregnancy. Pregnant women are directed to engage in risk-averse behaviours such as ensuring optimal nutrition, avoiding alcohol and caffeine, having additional vaccinations and sleeping on their side, for the good of their baby, and are even expected to self-monitor their mental state to ensure their baby is protected from potential harms caused by stress (Lupton, 2012). In this way, the medical gaze renders women's bodies docile through demands for self-regulation, control and discipline (Cummins, 2014). Embedded within Western neoliberal contexts and ideologies, the pregnant woman is held individually and solely responsible for the health of her growing baby, and it is her personal choices that will determine success, or failure (Alcalde, 2013). She is expected to accept medical authority over her body and adhere to medical advice to ensure the best health outcomes for her baby. As carriers of their 'precious cargo' (Lupton, 2012), this responsabilisation of risk provides the conditions of possibility for accusations of deficiency or even deviance if women 'fail' to uphold and obey the numerous expectations demanded of them. In this sense, pregnant mothers can be accused of being "weak and volatile, prone to falling from grace whether through ignorance or temptation, and thus allowing substances into their bodies which may adversely affect their foetus" (Lupton, 2012, p. 337). These same neoliberal values of the responsible individual also provide the conditions for shame and self-blame when a woman's baby dies during pregnancy; because

they are solely responsible for the health and wellbeing of the developing baby, if a woman experiences miscarriage, it must have been something they did, or did not do.

### *The (Ab)normality of the Miscarrying Body Under the Medical Gaze*

Like pregnancy, miscarriage falls under the medical domain while also being viewed as a normative biological process related to reproduction. Pregnant women who show signs of miscarrying will often seek advice or confirmation from healthcare practitioners such as midwives, general practitioners or urgent care providers. In many cases, miscarriage will be identified during routine antenatal appointments, such as during a scheduled ultrasound. Medical care for miscarriage largely consists of diagnosis and treatment of the biological body. Miscarriage can be managed expectantly, which involves waiting for the natural passing of the baby and pregnancy tissue from the body, medically through taking tablets to aid the miscarriage process, or surgically using a dilation and curettage (D&C)<sup>1</sup> procedure (Coomarasamy et al., 2021). Under the medical gaze it is the body of a miscarrying woman that is ‘seen’, namely her reproductive organs, and her baby is often reduced to a ‘biological by-product’, ‘medical waste’, or ‘the product of conception’– ‘tissue’ that needs to be expelled from her body (Andipatin et al., 2019). Through the medical gaze, what goes unseen, disregarded and/or denied is the woman as a mother and as a human being who is going through an affective and embodied meaningful loss, and her baby who has died.

The reductive focus on the pregnant body, and constructions of babies as ‘tissue’, has implications for how we can understand, and therefore respond, to miscarriage. Historian Leslie Reagan argues that representations of miscarriage in Western society have changed “from hazard to blessing to tragedy” (Reagan, 2003, p. 359). At the beginning of the twentieth century pregnancy and miscarriage were sources of physical harm and hardship for

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<sup>1</sup> A dilation and curettage (D&C) is a surgical procedure that involves opening the cervix and, in the case of miscarriage, removing the baby and any other pregnancy tissue from the uterus.

many women, due to maternal mortality and the health impact and financial strains associated with complicated pregnancies or deliveries, however by mid-century, as scientific and medical institutions became more dominant, and medical technologies and intervention increased, miscarriage became a blessing: a natural occurrence that spared a couple from the bad fortune of an ‘abnormal’ child (Reagan, 2003). Reinharz (1988) suggests that miscarriage is conceptualised as “nature’s way of weeding out defective fetuses” (p. 86), a ‘natural’ process that is positive and essential. When miscarriage is constructed this way, where the baby is not a baby, but instead a ‘defective fetus’, and the woman the carrier of such a deflection rather than a mother, the ‘humanness’ of both the baby and the mother is denied, reducing them to biological components and processes. We hear this notion of miscarriage as a ‘blessing’ echoed when women who miscarry are placated with well-used phrases such as, “It was for the best” and “It’s nature’s way”. Reducing miscarriage to a biological event that was ‘for the best’ constrains the possibility of acknowledging the emotional and affective experience of the mother, and a meaningful relationship between a mother and her baby.

Turning for a moment to language, we can ponder how even the term *miscarriage* perpetuates and reinforces the notion of a defective biological process. Looking to the etymological foundations of this word we can see that it is laden, comprised of *mis-* which means *to mistakenly, wrongly or badly*, and *-carriage*, which means *to carry*. Browne (2018) asserts that this term produces assumptions of failure of the mother to adequately ‘carry’ her baby which can induce notions of blame, negligence and deficiency for the mother. She may feel that the ‘failure’ of her risky body to protect her growing baby represents a failure of her maternal responsibility to her child. Unsurprisingly, feelings of guilt and shame are well-documented responses for women who miscarry (Adolfsson et al., 2004; Bellhouse et al., 2019; Broquet, 1999; Cesare et al., 2020; Frost & Condon, 1996b; Harvey et al., 2001; Kukulskienė & Žemaitienė, 2022). Bohn (2023) argues that terms such as *miscarriage*,

*spontaneous abortion* and *pregnancy loss* are “referentially ambiguous”, as “despite appearing to refer to one event, they often refer to two distinct events: the baby’s death and his (extremely) preterm delivery” (p. 266). Terminology that focuses on preterm delivery while excluding the baby’s death, asserts Bohn, can inhibit the realisation and expression of a diverse range of emotional responses, particularly grief. Conversely, emphasising the baby’s death rather than preterm delivery can minimise the difficult and often traumatic physical experience of miscarriage, which may contribute to feelings of shock and unpreparedness, and neglects to acknowledge or attend to the mother’s embodied experience. Instead, Bohn (2023) proposes the adoption of two terms, *intrauterine death* and *preterm delivery*, to convey “all of what happened” (p. 277): a baby lived and died within its mother’s body, and passed from its mother’s body.

The medicalisation of miscarriage also governs, enables and constrains the ways in which women can experience miscarriage. Andipatin et al. (2019) explored the way biomedical discourses are taken up and shape women’s understandings of pregnancy loss. They argue that whilst many women may wish to understand the reason for their loss, generally miscarriage will not be medically investigated unless three consecutive miscarriages have occurred, producing unequal power relations within the medical encounter, as women are forced to accept little or no explanation for what has occurred and are unable to expect support or care post-miscarriage. Furthermore, within such an encounter, women may feel expected to accept their loss as ‘normal’, unimportant and unworthy of medical attention, closing down spaces to understand, and respond to, miscarriage as a significant experience for many women, and de-legitimising affective and emotional responses to the loss of their baby. Andipatin et al. (2019) argue that not only are dominant biomedical discourses taken up by women who miscarry, but they also pervade and propagate societal understandings of miscarriage and as such, infiltrate social encounters and responses. The positioning of

miscarriage as common, normal and medically unimportant produces and maintains a lack of acknowledgment and recognition that, for many women, something of value—a baby—has been lost and will be grieved.

### ***Troubling the ‘Care’ in Healthcare***

The medicalisation of reproduction positions healthcare practitioners as the most appropriate response for women who are seeking advice, support and care for miscarriage, but given that, under the medical gaze, miscarriage is reduced to biological bodies and products of bodies, embedded within assumptions that miscarriage is a ‘normal’ event of no significance—a passing of defective tissue and products of conception—we can begin to question understandings, practices and experiences of ‘care’ for women who have miscarried in the healthcare context.

Even when we understand ‘care’ as tending to biological bodies in the healthcare context, existing literature points to a lack of adequate medical care for women during and following miscarriage. Reinharz (1988) attests that miscarriages defy conventional medical categories, as they are seen as “neither illness nor injury, neither a life to be saved nor a death to be mourned” (p. 88), and their frequency and perception as a ‘good’ and helpful biological process work to render them of little interest in the medical field. As Reinharz (1998) professes, “Physicians consider miscarriages “humdrum and dull” because they are rarely life-threatening, require only routine intervention, and generally cannot be reversed” (p. 4). Similarly, Hardy and Kukla (2015) suggest that for healthcare professionals, miscarriage signals “the end of a medical narrative rather than an event within one” (p. 106).

While healthcare practitioners may regard miscarriage as normal, routine, and of little medical interest, women who experience miscarriage can view miscarriage as a medical emergency that demands urgent care. Women in a study by Andipatin et al. (2019) reported that surgery to resolve their miscarriage was treated as non-urgent by healthcare practitioners,

leading the authors to suggest that healthcare practitioners perceive the procedure as involving “medical waste that may be disposed of when doctors are available to do the job” (p. 555), whereas mothers are carrying their baby who has died inside of them which may feel urgent to resolve. We can also consider other aspects of miscarriage that may feel strikingly urgent for women. Particularly for those women encountering miscarriage for the first time, it is an unfamiliar, unknown and often harrowing embodied experience. It can involve blood loss, excruciating pain and heart-wrenching distress. In the case of threatened miscarriage, a woman may be desperate for someone to try to save her baby. When the response is to deny or delay care, or to send women home to cope without medical support because the miscarriage is ‘normal’ and ‘inevitable’, women’s own knowledge of what is happening for them and within their bodies, and their needs and wants, are ignored or delegitimised, with the assumptions, needs and wants of the medical institution outweighing and dominating over those of the woman.

The concern of inadequate ‘care’ in the healthcare system is a pressing concern given that previous research shows that healthcare professionals play a vital role in shaping the experience of miscarriage and influencing wellbeing outcomes (Bellhouse et al., 2019; deMontigny et al., 2017; Galeotti et al., 2022; Swanson, 1999; Watson & Jewell, 2018). The quality of healthcare services can have a direct influence on women’s mental health in the months and years following miscarriage (deMontigny et al., 2017), and, as part of that ‘care’, women often seek emotional concern, support and a feeling of connection from healthcare professionals (DeFrain et al., 1996). Frequently, however, healthcare practitioners are not providing the care that parents so greatly desire, with many parents feeling dissatisfied with the psychological and emotional care that they receive, reporting it to be overly-clinical, insensitive and lacking recognition of the emotional experience of grief and loss (Bellhouse et al., 2019; Cecil, 1994b; Galeotti et al., 2022; Geller et al., 2010; Jensen et al., 2019).

Many healthcare professionals also believe that psychological and emotional care should be improved within the medical response to miscarriage (Evans et al., 2002), and while they may feel confident in their skills and ability to provide what parents need, time and resource issues prevent them from being able to deliver adequate emotional care (Jensen et al., 2019). The barriers to receiving adequate care that attends to both physical and emotional needs can be due to the fragmented availability and accessibility of miscarriage services (Yang et al., 2022). The Lancet (2021) has recently issued a call to arms to move away from the “pervasive acceptance” (p. 1597) and long held minimisation and dismissal of miscarriage in the medical institution, and to instead regard miscarriage as a global issue that demands a collective and integrated response, rallying medical researchers, service providers and policy makers to overhaul medical care and rework the narratives that surround miscarriage. While this holds promise, we must acknowledge how pervasive and entrenched the medicalisation of miscarriage is, and the relative impossibility of a swift and transformative overhaul of the medical institution. As such, in the face of a medical system that we cannot count on in the contemporary context to provide responsive and adequate care for women who miscarry, we must begin to ponder alternative ways of strengthening our capacities for social and emotional support of miscarriage.

### **Honouring Women’s Stories of Miscarriage, Loss and Motherhood**

Despite the pervasive denial of women’s affective and embodied responses to miscarriage within the medical paradigm, there is a growing academic recognition and honouring of women’s emotional experiences that prioritises the emotional, and often enduring, impact of miscarriage for woman (Abboud & Liamputtong, 2002; Gerber-Epstein et al., 2009; Harvey et al., 2001; Meaney et al., 2017; Watson & Jewell, 2018). In stark contrast to the conceptualisation of miscarriage as an acute medical occurrence, miscarriage has been shown to be experienced as a major life event for many women (Harvey et al.,

2001). Rather than a moment in time, miscarriage can be understood as a journey (Fairchild & Arrington, 2023; Watson & Jewell, 2018) that “begins prior to conception and shapes perspectives throughout a lifetime” (Watson & Jewell, 2018, p. 6): a journey that can have an profound impact on a woman’s sense of identity (Frost & Condon, 1996; Gerber-Epstein et al., 2009; Smorti et al., 2021; Tian & Solomon, 2020; Trepal et al., 2005), her values, beliefs and perspectives (Krosch & Shakespeare-Finch, 2017; Watson & Jewell, 2018), and can change the way she interacts, relates to and connects with other people and with the world around her (Collins et al., 2014). For instance, Fairchild and Arrington (2023) found that women narrated miscarriage as a journey, beginning with a joyful pregnancy before transgressing into shattered hopes and dreams that brought about anxiety, uncertainty and a reckoning of what the future would hold. Maker and Ogden (2003) note that this journey often produces a delineation between a woman’s pre and post-miscarriage sense of self, and they travel this journey—moving and working through their experiences of shifting emotions and how they make sense of their past, present and future—in diverse ways. Likewise, Shreffler et al. (2011) found that the way a woman experiences and understands her loss within the context of her life shapes the way she navigates her grief and copes with the trauma of her experience; her beliefs about motherhood and her fertility, the extent of her desire for a baby, and her experiences after her loss all contribute to her experience of miscarriage. Women’s journeys of miscarriage need to be understood as an embodied experience whose meaning is embedded in the context of their unique lives and experiences.

### ***Stories of Grief***

A growing body of research is beginning to recognise the extent of grief and bereavement that women experience in miscarriage (Bellhouse et al., 2018; Brier, 2008; Conway & Russell, 2000; Davoudian et al., 2021; Flach et al., 2022; Frost et al., 2007; Frost & Condon, 1996; Janssen et al., 1997; Krosch & Shakespeare-Finch, 2017; Lang et al., 2011;

Meyer, 2016; Nikčević et al., 2007; Tian & Solomon, 2020; Trepal et al., 2005). Women often feel a sense of grief following miscarriage—a grief that has been recognised as similar in intensity and length as other forms of perinatal death (Toedter et al., 2001) and as substantial as grief following the loss of any loved one (Lok & Neugebauer, 2007). However, grief associated with miscarriage and other perinatal loss also holds unique qualities that differ to other losses. Alongside common grief responses such as shock, sadness, yearning and helplessness, women may experience self-blame and a questioning of their own femininity and sense of being a ‘woman’ (Davoudian et al., 2021). Furthermore, perinatal and miscarriage grief is complex and encompassing, speaking to multiple losses at multiple points in time both now and in the future. For women, there is a loss of the identity as a pregnant woman and denial of motherhood, the loss of the baby as a family member, the loss of the hopes and dreams for the baby, and of the imagined future that was to come (Brier, 2008; Davoudian et al., 2021; Harvey et al., 2001).

In perinatal bereavement grief can take on an ambiguous quality. Ambiguous loss is characterised as a loss that is missing an important component, in this case the physical presence of a baby, as well as lacking a sense of closure and clear understanding (Betz & Thorngren, 2006; Lang et al., 2011). The death of a baby can be ambiguous as women experience both the physical absence and psychological presence of the baby: their baby ‘exists’ for them in their thoughts and grief, and yet there is no baby to have, hold or mourn any longer (Cacciatore et al., 2008). Particularly in early miscarriage, mothers may not be able to meet and hold their baby, and therefore lack opportunities to create memories that are embodied or are socially recognised as a ‘meeting’ between a mother and her child (Davoudian et al., 2021). There is an absence of rituals and customs for miscarriage, limiting opportunities for bereaved parents to publicly grieve and come to terms with the death of their baby (Frost et al., 2007). Indeed, it was only very recently that miscarriage was

recognised in New Zealand legislation as a bereavement, granting bereaved parents leave from work to grieve their miscarried babies, as is offered for other forms of bereavement (Holidays (Bereavement Leave for Miscarriage) Amendment Act, 2021). With few socially recognised ways to grieve, parents may question whether what they lost *was* a baby, which comes as little surprise considering the heavy medicalisation of miscarriage where their babies are spoken of as ‘tissue’ and ‘defective fetuses’, leaving women questioning whether they are seen, and can see themselves, as “bereaved parents or as patients undergoing a medical procedure” (Lang et al., 2011, p. 190).

When we do not acknowledge miscarriage as a traumatic or significant event, or the mother and baby as ‘existing’ through the reduction to medical processes and entities, then we can struggle to see grief as an expected response to baby loss. As such, grief in the context of baby loss can be understood as disenfranchised grief, which refers to a state of bereavement that is “not openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p. 4). The lack of social recognition of grief after baby loss can prompt women to feel that their grief should not be expressed and exists only for them (Collins et al., 2014). Culturally, we hold certain ideals of what can be grieved, how, and for how long, and to stray from these normative notions makes grief a “tenuous and risky process, as it invites social criticism rather than social support” (Meyer, 2016, p. 1427). As such, women’s grief responses open spaces to pathologise women’s experiences through psychological discourses of depression, complicated grief or pathological grief (Brier, 2008; Flach et al., 2022; Frost & Condon, 1996; Janssen et al., 1997), and, indeed, the existing body of psychological research has a heavy focus on the psychiatric implications of miscarriage for women (Broquet, 1999; Davoudian et al., 2021; Farren et al., 2020; Frost & Condon, 1996; Gaudet, 2010; Herbert et al., 2022; Hunter et al., 2017; Kersting & Wagner, 2012; Krosch & Shakespeare-Finch, 2017; Lang et al., 2011; Lok et al., 2010; Lok & Neugebauer, 2007; Nikčević et al., 2007; Quenby

et al., 2021; Smorti et al., 2021), affirming and perpetuating miscarriage as a medical concern and categorising the grief and trauma response to the death of a child as pathological. Whilst the recognition of the psychological impact of miscarriage has enabled a greater acknowledgement and understanding of the breadth of many women's emotional responses to miscarriage (Broquet, 1999; Frost & Condon, 1996), opening spaces for pathways for more effective and responsive care (Galeotti et al., 2022; Jensen et al., 2019), it also reproduces assumptions of deviance and deficit, rendering women's responses to the death of a child as abnormal and unreasonable. Women's emotional responses become symptoms of psychological disorder and her personal 'failure' to maintain mental well-being after miscarriage. Thus, from within the medical paradigm both a woman's mind *and* her body can be seen as defective. Her body fails to carry her baby safely, and her mind fails to respond appropriately.

### ***Stories of Guilt and Failure***

Given that women are constructed as 'risky bodies' within the medical gaze, and constructed as the 'protector' of their 'precious cargo' (Lupton, 2012), many women can struggle with feelings of guilt and 'failure' when their baby dies (Adolfsson et al., 2004; Bellhouse et al., 2019; Broquet, 1999; Cote-Arsenault et al., 2001; Harvey et al., 2001; Quenby et al., 2021). Women may feel guilty if they believe they were responsible for the miscarriage, either that they did something wrong, or that there was something 'wrong' with them physically (Frost & Condon, 1996; Harvey et al., 2001). Frost and Condon (1996) argue that dominant narratives and messaging conveyed in fairy stories and fables can

instil into us the notion that "bad things happen to bad people" and "good things happen to good people" (who can reasonably expect to "live happily ever after"). If tragedy strikes, we are primed to attempt to make sense of it as being a punishment for badness. (p. 56).

Thus, we can recognise feelings of guilt related to miscarriage as emergent from expectations of womanhood and motherhood embedded within neoliberal ideology, where women are positioned as personally responsible for the health and survival of their developing baby, and any harm or misfortune that befalls the baby becomes a personal deficiency or failure (Alcalde, 2013). From this perspective, women may experience guilt as they hold themselves responsible and accountable for the death of their baby, the ‘failure’ of their body, and for their own emotional pain.

### *Stories of Motherhood and Miscarriage*

Miscarriage can impact the way a woman identifies as a mother, and, indeed, as a woman given discourses of motherhood as an expectation or ‘achievement’ for women (Frost & Condon, 1996; Gerber-Epstein et al., 2009; Reagan, 2003; Russo, 1976), and this impact can be experienced in diverse and complex ways. Maternity is associated with successful and completed femininity, due to dominant social ideals that uphold motherhood as intrinsic to womanhood, where womanhood and motherhood are perceived as going hand-in-hand (Russo, 1976). In our society, argues Russo (1976), women are mandated to become mothers; there is an expectation for women to bear at least two children and to raise them well. A “conservative gender ideology that treats motherhood as woman’s greatest achievement and its denial as woman’s greatest suffering” (Reagan, 2003, p. 369) provides the conditions of possibility for women who are childless to be understood as a site of unrealised potential, deficiency or deviance, and lacking (Frost et al., 2007), where women without children have ‘failed’ to successfully practice and embody ‘womanhood’ (Frost & Condon, 1996; Layne, 2003). Miscarriage can undermine the social expectation that a woman will provide children for her husband and her family (Adolfsson et al., 2004) and can threaten her belief in her own fertility (Fairchild & Arrington, 2023; Gerber-Epstein et al., 2009; Meaney et al., 2017). When motherhood is positioned as “essential, imminent and natural in women’s life”

(Gerber-Epstein et al., 2009, p. 22), women are commodified as producers of children and their bodies as “the machines that create bodies-as-products” (Cummins, 2014, p. 38), placing demands on women that can lead them to question their ability to take up the position of ‘woman’ within their sociocultural context.

When we conceptualise motherhood and the identity of mother as a developmental task for women to achieve, miscarriage becomes an ‘interruption’ and works to disrupt and deny women’s ability to be seen as, and identify as, a mother (Trepal et al., 2005). This is especially so if the miscarriage occurs in a woman’s first pregnancy and she does not have any living children with whom she can fulfil and embody her ‘motherly duties’ (Lindemann, 2015). However, Lindemann (2015) argues that this conceptualisation of what it means to be a mother cannot account for how women make sense of and understand themselves in relation to their pregnancy and baby, arguing that “[even if] she is already a mother, she may still experience the loss as a blow to identity: she will not be *this* child’s mother” (p. 85). Therefore, spaces to acknowledge how women experience their identity, in particular their maternal identity, must take into account women’s own subjective embodied experiences and how a woman conceives of *herself* in relation to her pregnancy and her baby.

While some woman who miscarry report a loss of their motherhood identity (Gerber-Epstein et al., 2009; Harvey et al., 2001; Watson & Jewell, 2018), other women can feel “abandoned between the world of motherhood and non-motherhood” (Harvey et al., 2001, p. 11), speaking to the liminality of miscarriage as an event of which “entities and conditions slip between recognised categories—a growing entity that is not quite human, yet not other, or a woman’s identity as somewhere between a mother and not” (Miller, 2015, p. 142). While pregnant women may identify as mothers in ways that feel meaningful to them, they struggle, however, to retain this identity socially when miscarriage occurs. Because their babies are no longer living, they do not have the ‘markers’ of motherhood (i.e. a child to hold) and cannot

fulfil the expectations and practices associated with normative mothering. They may feel 'mother' to their lost babies, but that the world has forgotten or denied them the legitimacy and acceptance of their identity as mothers.

Layne (2013) refers to the 'realness problem' of baby loss, whereby "the realness of the baby, the mother, the event, and the legitimacy of grief are simultaneously challenged" (p. 17). During pregnancy, Layne argues, babies become 'real' and are constructed into personhood by the parents and by other people. Early in pregnancy, many women identify as a mother (Abboud & Liamputtong, 2002; Harvey et al., 2001), embarking on, or preparing for, their role as 'mother' by loving and caring for their unborn child, pondering names, planning for their future and envisioning the baby's place within the family (Adolfsson et al., 2004). We collectively agree on the 'realness' of a baby when we hear their heartbeat, see them wiggle on a sonogram, give them nicknames or knit a blanket in anticipation of their birth. Yet when a baby dies in pregnancy, both the support provided for parents and acknowledgement of the realness of the baby are often revoked, and those same people who helped mothers to construct the baby as real will often act as though nothing meaningful occurred (Layne, 2013). In response, bereaved parents may use material things, the realness of which cannot be denied, to honour the existence and realness of their babies (Layne, 2000). Through materiality, parents can make a claim of their babies realness; displaying sonogram photos shows us a baby lived, handprints and footprints signal the baby's humanness, the planting of a tree memorialises the death, and jewellery worn by the mother reminds us the baby is precious, and connected to her in an enduring way. So too, do these material acts and artifacts affirm the existence of a 'real' mother.

Although miscarriage is frequently presented as a challenge to a woman's sense of womanhood, Fairchild and Arrington's (2023) narrative study offers a more complex view that resists the denial of women's claim to motherhood and womanhood. While many women

felt miscarriage was a challenge to their identity and role as an emerging mother, other women drew on the common occurrence of miscarriage to reason that it made them feel like even *more* of a woman, with one participant stating, “It’s something that so many women go through. I just feel like I’m part of the club I guess!” (Fairchild & Arrington, 2023, p. 262). As a common experience, miscarriage offers the potential for meaningful connection through womanhood, yet this joining together is only possible if women can speak of their experiences with others, and be given space to acknowledge the complexity of their grief and emotional and physical experiences.

### **The Silencing of Stories of Miscarriage**

While speaking together about miscarriage can foster connection, recognition and understanding, spaces to talk about miscarriage are limited. Globally, miscarriage is an experience shrouded in silence and stigma (World Health Organization, 2024). Bellhouse et al. (2018) refer to a “vast silence” (p. 8) of miscarriage (a silence that Miller (2015) argues spans cultural, interpersonal, historical and scholarly spaces) that is so pervasive that miscarriage goes largely unspoken and socially obscured to the extent that women have little understanding of it until experiencing it themselves (Frost et al., 2007). They may be unaware of those women in their social network, including close family relationships, who have also experienced miscarriage and therefore could be a source of information, support and understanding (Cecil, 1994a; Meaney et al., 2017). Thus, while miscarriage is a common experience for women, it is largely an unspoken one.

The silencing of miscarriage can be linked to the tendency to not talk about pregnancy in its early stages. Couples who become pregnant often enact the ‘12 week rule’, a commonplace and prevailing social convention whereby pregnancy is kept secret in the first trimester (Bute et al., 2019; Ross, 2015). As the risk of miscarriage is much higher in the first trimester (Ammon Avalos et al., 2012), Bute et al. (2019) suggest that the 12 week rule

encourages couples to only announce a pregnancy when the risk of miscarriage has largely subsided. Indeed, an exploration of women's attitudes toward pregnancy disclosure found women to be acutely aware of the elevated risk of miscarriage in the first 12 weeks and, in light to this, to practice secrecy and suppress their own excitement about the pregnancy until the risk of miscarriage had waned (Ross, 2015). Thus, the rule that we do not speak of early pregnancy signals another rule: that should miscarriage occur, it should not be spoken of (Bute et al., 2019). We create a norm of silence for both early pregnancy and miscarriage, and in doing so make it 'normal' for women to be silent about their own affective and embodied experiences.

### ***Silencing the Loss***

As miscarriage goes unspoken, and is largely relegated to a private experience, many people hold broad misconceptions of miscarriage. Survey studies have found that the majority of people perceive miscarriage to be a rare event and underestimate how common it is (Bardos et al., 2015; McCarthy et al., 2020). Furthermore, there is a tendency to regard miscarriage as an insignificant and transitory event from which women will swiftly recover with no enduring emotional impact (Frost & Condon, 1996), and while a survey study by Renner et al. (2000) found that miscarriage is recognised as a loss (and as a loss that a woman may mourn), understandings of a woman's emotional response to the death of her baby during pregnancy, and of the meaning of the miscarriage for her, are limited. Grief is presumed to be more severe the longer a baby survives the pregnancy, yet research shows no association between the length of time a baby lived during pregnancy and how intensely a mother feels her grief (Plagge & Antick, 2009). Reinharz (1988) outlines a paradox whereby miscarriage is presumed to be insignificant if a woman already has living children, and also when a woman does not have living children if she is young and there is the likelihood of future children. Here we can see the norms and expectations of womanhood at play: as long

as there are still the mechanisms for upholding the expectations of womanhood through successful mothering, there is assumed to be no 'loss' of any significance. The woman has not lost the possibility of motherhood, or the means of fulfilment of normative womanhood, thus she is not seen to suffer. Without a social conversation about miscarriage, and spaces to speak about it, broadly held misunderstandings and misconceptions can constrain and deny our responses of care and support to women's experiences of real and substantive grief.

### ***Cultural Silence***

Our silencing of experiences of miscarriage can be linked to a broader fear of death that is apparent in Western society (Frost et al., 2007; Reinharz, 1988). Miscarriage, argues Frost et al. (2007), is a "paradigmatic example of the sequestration of death, both in the sense that most women...know little about it until they experience it themselves, and in the sense that its occurrence is surrounded by secrecy and is hidden from public view" (p. 1004). Even using the term 'baby loss' avoids death, attests Reinharz (1988), because the baby is not dead, but instead 'lost'.

While other forms of death and bereavement are often marked by tributes, death certificates, flowers, condolences and funerals, there is a notable void of recognition, ritual and custom for miscarriage. Layne (2013) illustrates this starkly by pointing to the lack of industry related to miscarriage, stating, "At the level of popular culture, one of the clearest indicators of the culturally sanctioned nonexistence of these events is the fact that there are no greeting cards for such occasions." (p. 69). The taboo and secrecy surrounding miscarriage, argues Layne (2013), are signals of the great significance and importance miscarriage holds, whereby silence operates as a form of cultural prohibition sheltering society from uncomfortable truths, where public and social acknowledgement of miscarriage conveys "an unwelcome reminder of the fragility of the boundary between order and chaos, life and death" (Layne, 2013, p. 65). To acknowledge miscarriage as the death of a cherished

baby and a woman's response as the grief of a mother is to turn towards confronting notions of human vulnerability and immortality, challenging our belief in the life-giving and life-saving abilities of science and medicine as we are brutally reminded that death is largely out of our control. Furthermore, the death of a baby during pregnancy shatters our narrative of pregnancy and motherhood as an idyllic, joyous time in a woman's life, and compels us to accept the complex and painful reality of motherhood in all its diverse forms.

Whilst silence provides protection from these frightening realities that thwart our understandings of how life should be, the silence forces women to grieve alone, constraining our understandings miscarriage and closing down spaces to recognise and allow space for the expression of real and substantive grief. If we want to understand and be responsive to women's emotional responses to miscarriage then we need to look to the meaning that a pregnancy and the death of a baby holds for a particular woman in her particular context (Corbet-Owen & Kruger, 2001), and we need to open spaces to speak of, and to hear, subjective and embodied experiences in order to enable women to feel supported when experiencing such complex, unique and meaningful grief.

### **Social Support**

The support and care that women receive from others is pivotal in shaping the way women experience miscarriage, however the lack of social conversation about miscarriage means that many women receive little acknowledgement or support from their family and friends (Hiefner, 2020; Rowlands & Lee, 2010). Feeling supported and cared for through miscarriage can help women to navigate their grief, loss and distress following the death of their baby during pregnancy (Alqassim et al., 2022; Bellhouse et al., 2018; Davoudian et al., 2021; Rajan & Oakley, 1993; Rowlands & Lee, 2010). A study looking into women's preferences for miscarriage support found that support is both desired and necessary, and is urgently needed as soon as possible after miscarriage and in the days and weeks that follow

(Séjourné et al., 2010). Women feel well supported when the care they receive is responsive and can meet their various needs, such as their needs for information, empathy, understanding, consolation, connection, opportunities to talk, and help with the tasks of everyday life such as cooking, shopping or caring for children (Alqassim et al., 2022). Across the academic literature social support is loosely defined and conceptualisations are expansive. Sources of support include partners, family and friends, as well as healthcare providers and specialised care providers such as therapists, counsellors and baby loss support groups.

### ***Partner Support***

A number of studies have found that for many women, their partners are often their primary source of support (Alqassim et al., 2022; Bellhouse et al., 2018; Cecil, 1994a; Conway, 1995; Conway & Russell, 2000), providing physical presence and encouragement, prioritising the women's needs and feelings over their own, helping them to feel more positive, and sharing in their feelings of grief (Abboud & Liamputtong, 2005; Bellhouse et al., 2018; Cecil, 1994a). Interviews with Australian women showed that whilst sometimes losing a baby deepened a couple's connection, feeling as though their partner did not fully understand their experience could induce feelings of isolation, and there remained a gap between the support women needed from the partners and the support partners provided (Collins et al., 2014). Likewise, feeling as though they are grieving more intensely, or differently, than their partners can leave women feeling alone, misunderstood and disconnected, threatening the stability of the couple's relationship (McDonald et al., 2022). Thus, while partner support is viewed as important, the specific and unique experience of women through miscarriage can mean that partner support is sometimes not experienced as adequate, or meaningful, not only causing troubles in the relationship but compounding feelings of isolation.

### *Friend, Family and Community Support*

Much like research concerning partner support, research into social support after miscarriage from family and friends can be both a positive and nurturing experience, and can amplify feelings of isolation and distress. Women report that they appreciate displays of empathy and acknowledgement of their grief, alongside tangible forms of support such as receiving meals, gifts and childcare, enabling the women to have the space to attend to their emotional experience (Alqassim et al., 2022). Support from women who have also experienced the death of a baby during pregnancy is highly valued by those who miscarry, with women reporting that these encounters feel comfortable, validating and helpful due to shared understandings and connectedness (Alqassim et al., 2022; Bellhouse et al., 2018; Hiefner, 2020; Rajan & Oakley, 1993; Rowlands & Lee, 2010; Séjourné et al., 2010). However, women also report that expectations for support from friends and family members often fell short, where close friends and family did not acknowledge their experience as significant, and could not recognise that a much loved baby had died (Rowlands & Lee, 2010). When friends and family are unable to acknowledge the ‘realness’ of the babies lost, the significance or trauma of miscarriage, or the women’s grief, it can make the women feel alone and isolated; as if their baby, and this loss, did not and does not exist to anyone else but them.

Women’s accounts of social support speak to the fraught nature of expressing grief in the context of miscarriage. Women feel that their grief makes other people uncomfortable and that people are not able to cope with, or be around, their grief (Rowlands & Lee, 2010). There is a social expectation that women ‘move past’ the miscarriage swiftly, and are provided with platitudes rather than genuine attempts to understand what women are going through (Alqassim et al., 2022). Telling women to look for ‘silver linings’ and to focus on future pregnancies dismisses loss and grief as trivial (Bellhouse et al., 2018), positioning

miscarriage as a 'blessing' and signalling to women that what is important is not the death of her baby, but to become pregnant again so that she can have a living baby in her arms.

Social interactions of support become even more fraught when women within care networks are pregnant, or have young babies, themselves. Following miscarriage, women may find they are hit by 'waves of emotions' when they are around pregnant women or newborn babies, which can be salient reminders of what has been lost (Swanson, 1999). As such, they may keep their distance from people who otherwise may have been sources of support (Collins et al., 2014). Furthermore, some women feel that their pregnant friends avoid them, or refrain from speaking of babies or children around them (Fairchild & Arrington, 2023), producing barriers in their friendships and connections.

### ***Online Support***

Given social support is important to women after miscarriage, but the silencing of miscarriage can mean that women are unable to speak of their loss and may be unaware of who in their usual social networks has experienced miscarriage that they can turn to, opportunities for meaningful connection with women who know first-hand what it feels like to grieve the loss of their baby are often constrained, and many women are beginning to turn to online spaces to connect with others who have had similar experiences and to develop their own spaces for support, comfort, understanding and recognition. Women are finding connection and community through online message boards, blogs and social media sites such as Facebook, Instagram and Twitter, using online spaces to express their thoughts and feelings about miscarriage, to elicit support and offer support to others, to bemoan the scarcity of support and care received offline, and to discuss and criticize the social conditions, legislation and medical provision that add to the distress of women who experience miscarriage (Cesare et al., 2020; Gold et al., 2012; Hardy & Kukla, 2015; Mercier et al., 2020). Notably, Gold et al. (2012) found that while roughly half of the women they surveyed

who participated in online baby loss message boards had experienced their loss in the year prior, many women were five, ten, twenty or more years from their loss, signalling miscarriage as a profound and significant experience that endures and extends well beyond the ‘event’ and into the future, where many women continue to desire connection and support long after the miscarriage has occurred. This desire for enduring connection emphasises the need to adopt a long-term view of miscarriage and social support that can adapt to and meet the needs of women over time.

Online platforms can provide women spaces where they can publicly acknowledge and speak about miscarriage in ways that may not be available to them in other social settings. Online spaces can provide opportunities for women to story their experiences and express their understandings of themselves as ‘mothers’ within a society that largely denies their motherhood (Hardy & Kukla, 2015). Within these online communities women are able to honour and memorialise their babies in ways that are not possible or acceptable in many offline social environments (Gold et al., 2012; Mercier et al., 2020). Photographs and stories of babies that have died can be shared and met with validation, non-judgment, care and love, whereas offline they may be seen as inappropriate or as an expression of grief that is abnormal. In online spaces, women are coming together to connect and grieve in ways they need and desire: diverse ways that often defy our normative understandings of what can be grieved and how.

### **The Present Study**

Miscarriage is a significant, profound and sometimes traumatic event, and many women experience notable grief and distress, as well as challenges to their identity as a mother and a woman. The dominant approach to care is through the medical system, which can deny or dismiss the emotional responses and needs of women. Recent research by Yang et al. (2022) has shown that access to services and support after miscarriage in Aotearoa New

Zealand is inequitable and fragmented, with barriers to care including geographic location, cost of counselling, limited availability of professionals and gaps in communication and between services. Appropriate healthcare provision is hampered by systemic and organisational factors, such as care being provided by junior staff in emergency departments and maternal healthcare systems designed for the mother-baby dyad, and there is a lack of coordinated care and clinical pathways to follow-up with women and link them to community support groups and services. To ensure women's wellbeing is better supported during and following miscarriage, urgent solutions are needed at systemic, organisational and community-levels (Yang et al., 2022). The need for improved community level care has also been highlighted by Dawson et al. (2019) who attest that the unique historical, bicultural and political context of maternal inequalities in contemporary Aotearoa New Zealand call for holistic approaches that emphasise wrap-around care, self-determination and community participation to combat barriers to equitable outcomes.

Given the health system is strained and struggles to provide the holistic care that women need, there is a need to turn our attention towards how we can 'fill the gaps' in the care of women experiencing miscarriage through better social support. As has been discussed through engagement with the literature, social support is vital, but is also often complex, fraught, inadequate and can do more harm. Given that during and following miscarriage women's interpersonal interactions are "pivotal in shaping the entire miscarriage experience" (Rowlands & Lee, 2010, p. 283), and that instances of support are broadly perceived as lacking, insensitive and invalidating, understanding the breadth and complexities of social support and how it is experienced is vital if we wish to improve care and support for women whose babies die during pregnancy.

As such, this research aims to explore how women experience social support during and after miscarriage in the context of Aotearoa New Zealand, growing a more

comprehensive understanding of what it means for women to be supported through miscarriage in order to identify avenues to strengthen and expand our capacity to care. From my engagement with the existing literature I believe that it is vitally important to undertake this endeavour through listening to women, understanding that women's experiences become meaningful within the context and unique biographies of their lives, and knowing that their stories of miscarriage are subjective, complex, embodied, and so often go unspoken and unheard. Therefore, this research aims to privilege the lived experiences of women by asking them how they understand their experiences of miscarriage embedded within their networks of support; asking them to speak of how their needs were met and/or unmet, and how they could relate and to be related to, within the bounds of the social conditions of this social and historical location. My hope is that hearing women's embodied wisdom and knowledge can propel us toward transformative, emancipatory outcomes, calling the systems of meaning making that constrain and subjugate women's voices of miscarriage to account, and moving beyond reductive and pathologising conceptualisations of miscarriage towards more situated, more expansive understandings of the experience of miscarriage and social support, so that we may grow in our capacity for care and connection.

## **Chapter Two: Methodology and Method**

### **Theoretical Considerations**

At the heart of this research is my desire to open spaces that privilege women's voices, stories, experiences and lives, enabling us to truly listen to diverse stories that speak to the nuanced lived experiences of miscarriage as embedded in social life. Ontologically, it was important for me to adopt a relational approach in order to uphold women's reality of miscarriage through the honouring of human relationships, interactions and engagement, as the meaning of miscarriage and social support for women is grounded in their relationships with the people in their lives, embedded within broader political, social and cultural relations, and, in the context of this research, also through their relationship with me.

From this project's conception I felt a strong pull toward adopting a feminist methodological approach, recognising the highly gendered nature of miscarriage, and, as explored in the literature review, the powerful social and cultural gendered norms surrounding women's bodies, pregnancy, birth and motherhood that enable and constrain how miscarriage is experienced for, and understood by, women. Taking up a feminist methodological perspective, I aim to open spaces for the telling of women's stories and honouring of women's embodied, lived experiences of the way miscarriage and social support is experienced. Furthermore, in aligning with the objectives of feminist research to enhance women's lives (Letherby, 2003), my intent for this research is to grow our understandings of the unique challenges surrounding miscarriage and social support for women, and engage possibilities for how we can work together to respond to, and support, women who miscarry in our communities.

### ***Feminist Standpoint Epistemology***

This research project is guided by feminist standpoint theory, a critical feminist perspective that upholds women's lives as privileged sites of knowledge. Feminist standpoint

theory calls traditional forms of knowledge into question, rejecting the positivist notion that science can be value free, apolitical, and that objective truth exists ‘out there’ waiting to be discovered by a neutral observer (Letherby, 2003). Decontextualised knowledge claims are criticised as “god tricks” that promise “vision from everywhere and nowhere equally and fully” (Haraway, 1988, p. 584), evading accountability by failing to acknowledge location and positioning, and as such, rendering such knowledge claims ‘irresponsible’. Instead, feminist standpoint theory engages with the notion of objectivity differently, suggesting “only partial perspective promises objective vision” (Haraway, 1988, p. 583). In other words, feminist objectivity relates to situated knowledge that, while limited and partial, is locatable and enables “...the joining of partial views and halting voices into a collective subject position that promises a vision of the means of ongoing finite embodiment, of living within limits and contradictions—of views from somewhere” (Haraway, 1988, p. 590).

Taking up feminist standpoint theory enabled me to privilege women’s lives as sites of situated knowledge, and furthermore, enables exploration of how marginalised voices are embedded in ‘the wider social order’, regimes of intelligibility and subjectivity, and gendered social power relations (Harding, 1992). Women with lived experience of miscarriage occupy a unique standpoint, and, as argued in Chapter One, their ability to speak from this standpoint is often silenced and subjugated through social and cultural forces of disenfranchisement that render the experience of miscarriage unspeakable or pathological. Therefore, opening spaces to listen to women from their vantage point affords critical visibility of the social conditions and power relations that silence their stories of miscarriage. From this perspective we can engage with how the knowledge claims and practices of social structures and institutions, such as medicine and healthcare, dismiss and minimise women’s pain and suffering, downplaying miscarriage as mundane and insignificant. As urged by Haraway (1988), feminist accountability requires “knowledge tuned to resonance, not to dichotomy” (p. 588).

The ability to both honour situated perspectives, and acknowledge how they are embedded in sociocultural context, enables a critical examination of dominant ways of knowing as forces that are entwined with and shape everyday lives and experiences, and in doing so, open up potentials and possibilities to respond differently to support and care for women in their journeys through miscarriage. To come to know miscarriage, we can turn to the ‘partial views and halting voices’ of the community of women who have lived experiences of miscarriage. Their/our stories are not homogenous and coherent, but rather diverse, contradictory and incongruous, complex and embedded in unique life context. The feminist standpoint perspective enables me to engage with, account for and embrace the complexity of experiences of miscarriage, hearing the stories of women’s lived, embodied experiences that, while partial and limited, converge in a collective story that can produce a richer, more cohesive and expansive understanding to support the goals of this research to grow our capacity for care and support for miscarriage.

## **Methodological Approach**

### ***Narrative Inquiry***

In the days, weeks and months following my first miscarriage I sought out other women’s stories. Not personally knowing of any women who had experienced what I had, I found that stories of miscarriage on podcasts, baby loss websites and in online support groups provided a sense of connection, helping me to feel less alone. As I listened I grieved the babies of women I had never met, alongside my own. Hearing other women speak about miscarriage helped me to feel like I could speak about it, too. To my surprise, when I began sharing my story with people in my life many women responded by disclosing their own stories of miscarriage to me. Perhaps, like me, these other women had felt unable to speak. Through silence, we had been disconnected from one another and from support and care. As the literature review has shown, women who have miscarried find other women who have

experienced baby loss to be a particularly helpful form of solace and support, thus reciprocal sharing of stories through a research encounter between women with lived experience of miscarriage is an apt approach for this endeavour.

Given that miscarriage is silenced, with few social spaces where stories can be readily told and heard, it has been important to me that this research did not reproduce or perpetuate silencing. A narrative approach to research offers a way for marginalised and silenced voices to be heard, opening the way for more expansive and complex understandings of women's lives (Miller, 2017). Therefore, narrative offered me an ethically sound and responsive approach for attending to miscarriage, resisting silencing through enabling untold or suppressed stories to be heard and witnessed in the context of relationships. As explicitly and inherently agentive (McAlpine, 2016), narratives enable story tellers with the means to express and navigate their hopes and intentions and to story the past while at the same time engage in sense-making about past experiences (Riessman, 2008). As such, participation in narrative research can provide comfort through experiences of connection and empathy, and the opportunity to create new vantage points from which to view one's own life (Bradbury, 2017).

Narrative is something known to us; we use narrative in everyday life. In narrative inquiry in social research, narratives "carry traces of human lives that we want to understand" (Squire et al., 2013, p. 2). The critique of the literature in Chapter One emphasised how women's meanings of miscarriage makes sense in the context of their own lives, and therefore taking up narrative inquiry enables women to tell us how they make sense of their experiences in context, attending to and honouring the meanings of miscarriage within the fabric of women's embodied and embedded lives. This approach enables me to place women at the heart of this research as "embodied and visible, since the lives from which thought has started are always present and visible in the results of that thought" (Harding, 1992, p. 452),

recognising that how a woman knows miscarriage is intrinsically connected to who she is, her relationships with other people and with her baby/babies, and to the way she understands and moves through the world. Furthermore, narrative inquiry can attend to the contexts and histories that envelop a story; storytelling is always embedded within the discourses and power relations of the particular sociotemporal context and moment in which it occurs (Riessman, 2008). Thus, narrative enables me to explore both the personal stories and the social narratives that surround and inform those stories.

Stories can be constrained, however, by the narrative frames available to us (Woodiwiss, 2017). Miscarriage is “typically excluded from social narrative space and particularly hard to articulate” (Hardy & Kukla, 2015, p. 123). More often than not, miscarriage is absent in dominant and narratives of motherhood and of reproduction, but at the same time is also understood within the context of those same dominant narratives (Fairchild & Arrington, 2023; Layne, 2003; Meyer, 2016). We know these narratives well: a couple meets, falls deeply in love, wants a baby together, then comes a pregnancy announcement, morning sickness, a growing bump and a healthy baby in arms. In Western society, cultural ideologies of coupledness, marriage, child-rearing and family are tightly held and broadly told (Addie & Brownlow, 2014; Chan et al., 2023; McKeown & Parry, 2019), and sitting snugly alongside these ideologies is the expectation that women will become mothers, raising at least two children, and raising them well (Russo, 1976). Miscarriage interferes with and ruptures these narratives. Encouragement to ‘try again’ pushes woman back toward the normative narrative, where the goal is a living baby, stifling any narratives that challenge fulfilment of normative motherhood, and making it difficult for many women to tell their stories without pathologisation or condemnation. The perception of miscarriage as “the absence of a story” (Hardy & Kukla, 2015, p. 123) signals the clear lack of space that

exists for miscarriage stories, or even for the existence of a bereaved mother and her baby who died.

Whilst dominant narratives of womanhood and motherhood constrain women's ability to tell and share their stories, there is also potential in opening spaces where new narratives can emerge—narratives that can enable the development of empathetic connections between women and their social support network and work to normalise and diversify the experience of miscarriage in our wider communities. Each story is taken as partial and limited, as “not everything that happens can be told” (Bradbury, 2017, p. 19), yet together women's stories can grow a collective and diverse story of miscarriage and motherhood. Thus, narrative provides an opportunity to re-story miscarriage, not just for women who tell their stories but for society at large. Empathy and connection can be enabled through inviting listeners not only to hear, but to step into the perspective of the storyteller, and, as such, narratives can do political work through prompting progressive social change, mobilisation and collective action (Riessman, 2008). Listening to women's previously silenced stories opens up possibilities for transformation, empowering marginalised voices through not only providing space for stories to be told, but to have a say in which stories should be told, how they should be told, and why (Sools & Murray, 2015), and those stories can impel us to do differently in the future. Thus, narrative research as a process and practice resists and challenges the subjugation of women's voices, privileging stories that have been suppressed through honouring storytelling and asking the question: “are there better stories that could be told to explain and improve the lives of the women in our research?” (Woodiwiss, 2017, p. 34).

### ***The Listening Guide***

As the aims of this project are grounded in my intent to open spaces to hear women's voices and stories, I sought an approach to narrative analysis that would allow women's stories to be expressed and heard for real. My concern was that fragmenting stories—pulling

them apart, isolating their parts, reducing them to themes, or focusing closely on content—might erase the stories that women so want to be heard, and would risk shedding context and with it the coherency and the associative meanings of the stories. Upholding context is vital, given we know that women’s experiences of miscarriage and social support are rendered meaningful and make sense within the contexts of their lives, and that powerful sociocultural forces shape the way women experience miscarriage.

Seeking an analytical approach that was responsive to the women’s stories and cohesive with my broader methodological stance, I came across *The Listening Guide* (Brown & Gilligan, 1993), a voice-centred relational approach to narrative analysis that promotes listening as a pathway to psychological discovery. A Listening Guide analysis is founded on the notion that the psyche, or the self, is “relational, dynamic, embodied, and in constant interaction with the social, material, and cultural contexts within which experiences occurs, and enters the social world through the telling of stories about one’s experience” (Tolman & Head, 2021, p. 152). This approach enabled me to engage with women’s stories while upholding embodiment in sociocultural and temporal context, and attending to the ways in which we make sense of our experiences in context through the telling.

At its heart, *The Listening Guide* is about listening to voices. Voices are embodied instruments of the psyche that enable a person’s ‘inner world’ to enter into social and relational space (Gilligan, 2015, p. 69). Listening to voice means to attend to its sound, rhythm and tone, the dynamic nature of its pitch, volume and movement, as well as to the feelings it evokes in others, what words the voice uses and when it is silent (Gilligan & Eddy, 2021). Listening for the musicality of a voice, we can begin to hear the multiple ‘voices’ that speak together, or separately, in diverse ways—perhaps a soft, despairing voice that gives way to a brazen, hopeful voice, or a terse voice of fury that speaks alone.

Through systematic and successive ‘listenings’ of a single oral narrative, the Listening Guide method demands that a researcher listens *differently* so that they may become “more engrossed, more sensitive, and more receptive—more connected” (Tolman & Head, 2021, p. 155) as they come to know a narrator’s story, their inner world and their social life. While listening, researchers are asked to embrace curiosity and to adopt a stance geared towards surprise and discovery, both to come to know the inner world of another (Gilligan et al., 2003) and to unshackle the analytical process from dominant cultural narratives and the assumptions that underlie them (Gilligan & Eddy, 2021). Thus, by listening differently we seek to ‘turn the volume down’ on what we know and how we know it, and instead attune ourselves to another’s voice and open ourselves to possibility and potential. As such, the Listening Guide enabled me to place women’s stories, voices and relational selves at the heart of this study, recognising that we must come to know them and their experiences before we can understand how they move through the world and consequently, experience support.

### ***Relational Ethics***

To me, taking a narrative approach was important to my ethics, and the ethics of the research I had hoped to conduct, where ethics is more than an institutional process of compliance, but is also a consideration of the ways in which we can relate, respond to and care for those in our communities that we have relationships with. This research was peer-reviewed and approved by The Massey University Human Ethics Committee (Application NOR 22/41), but my ethical obligations were not constrained to this institutional process. Rather, my ethical responsibilities have been front of mind throughout this project, grounded in my intent to care for and be responsive to women’s needs and wellbeing, to uphold integrity, dignity and care in my relationships with participants and with the bereaved parent community more generally. Therefore, I have engaged a relational ethics approach, which “requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds

to others, and take responsibility for actions and their consequences” (Ellis, 2007, p. 3).

Through embodying ‘human-heartedness’ (Hopner & Liu, 2021), relational ethics privileges collaborative, sincere and reciprocal relationships in research so that we may “strive to leave the communities, participants, and [ourselves] better off at the end of the research than they were at the beginning” (Ellis, 2007, p. 25).

For Braidotti (2013), ethics is concerned with “forces, desires and values that act as empowering modes of becoming” (p. 343). Drawing on Foucault’s notion of ‘counter-memories’ Braidotti (2013) argues that we can open spaces that call to account, and disrupt, relationships of power that maintain dominant, taken-for-granted stories and stifle quieter voices of those at the margins of society, making it possible to re-learn, re-story and re-think our processes of understanding and relating. Enacting and embodying relational ethics requires “a process of redefining one’s sense of attachment and connection to a shared world” (Braidotti, 2013, p. 193) so that we may expand our relational capacities through moving toward, imagining and realising potential and possibility.

Through engagement with the literature, I am aware of how women’s experiences of and responses to miscarriage are pathologised, and I was initially concerned that, through my research, I would risk re-producing deficit narratives when attending to women’s stories of sadness, anguish, pain and distress. However, taking up a relational ethics approach supports me to dignify the pain of miscarriage through listening to it, comforting it, giving it space to be held, and learning how to ‘do better’ from the stories women’s pain tells. Upholding relational ethics enabled me to take a strengths-based approach that resists reproducing processes of pathologisation, and at the same time honours women’s stories of pain and grief. As Braidotti (2018) argues, relational ethics enables a connection that “does not deny pain, trauma and violence, but rather proposes a different way of dealing with them” (Braidotti, 2018, p. 222) and as such, this research aims to honour women’s strength in enduring

traumatic experiences, privilege the meaning they find through their experiences, and, flowing from their wisdom, imagine possibilities for how we can improve our responses to, and support of, women who have miscarried, or will encounter miscarriage in the future. It is through hearing pain, and through listening empathetically, that we can be mobilised to do and be better, growing our capacity to care for women when their babies die during pregnancy.

### ***Cultural Responsivity***

Considering the bicultural context of Aotearoa New Zealand, I have endeavoured to honour and uphold the principles of Te Tiriti O Waitangi in my research design and objectives. I have reflected on my own positioning as tangata tiriti and obligations as a Treaty partner within this research, with particular regard for issues of power and control.

Cultural consultation was sought with a Kaupapa Māori senior lecturer from Massey University to ensure my practices and processes would protect and honour any Māori participants. I asked for guidance on how to ensure the research was open to and welcoming for Māori, particularly during engagement processes. I was encouraged to build connections and relationships through authentic and genuine engagement, being guided by the compassion and care that I have for all women who have experienced miscarriage, and cultivating relationships through shared experiences and through sharing my story, as well as hearing theirs. Manaakitanga and aroha guided all research relationships to promote interactions that embodied the expression of empathy, compassion, generosity, dignity and care.

The overarching purpose of this research is justice oriented, seeking useful and relevant outcomes that can contribute to better care outcomes for women who experience miscarriage in Aotearoa New Zealand. Currently, women who experience miscarriage face inequitable and fragmented access to services and support, contributing to poor health outcomes for

women who miscarry (Yang et al., 2022). This has particular pertinence for Māori for whom structural and systemic factors lead to greater disadvantage and disparities in maternal healthcare (Dawson et al., 2019). Utilising feminist standpoint epistemology while upholding Te Tiriti advances meaningful partnerships that privileges women's accounts of their experiences and interrogates the social and institutional power relationships that continue to hold the effects of colonisation in place.

### ***Community Engagement***

Although I knew my own story of miscarriage, and had engaged with the literature, I was also committed to engaging with those already working in the baby loss community to ensure that the direction, practices and processes of my research were responsive to and embedded in the community's needs and wants, and would be of direct benefit. Consequently, I consulted with Dr Vicki Culling, who is a bereaved parent and a leading support provider, advocate and educator within the baby loss community in Aotearoa. Dr Culling affirmed the need for research related to baby loss, and spoke of the prevailing misconception that the death of a baby during pregnancy is of little importance and will have a minimal impact on bereaved parents. She endorsed the value of listening to women's stories, and told me that women are *wanting* and eager to tell their stories, and benefit from doing so, confirming existing research that suggests sharing experiences of miscarriage in a research setting can promote feelings of acknowledgement and validation that support wellbeing and coping with loss (Gerber-Epstein et al., 2009; Kenney, 2009; Watson & Jewell, 2018).

I have been in regular communication with Dr Culling during the course of this project, and she has kindly gifted her time and wisdom when I have needed guidance. Furthermore, through Dr Culling I have been provided with opportunities to engage with and participate in the baby loss community. As a bereaved parent I have shared my story, alongside other bereaved parents, with midwifery and other healthcare professionals in

Aotearoa during regular educational webinars related to baby loss. Dr Culling also supported me to build relationships with other bereaved parents, researchers and healthcare professionals at a national baby loss conference. Through my immersion and participation in the baby loss community, my understanding of community need has become enriched, and I have continually worked to align my research design and practice to meet those needs.

## **Method**

### ***Participants and Recruitment***

I wanted to speak to women who had experienced miscarriage, however as noted in Chapter One, the notion of miscarriage is contentious, varied and hard to define. I have chosen to align my conceptualisation of miscarriage with the legislated definition of miscarriage in Aotearoa New Zealand, given my project seeks to explore women's experiences of miscarriage and social support within this geographical context. Participants needed to have experienced at least one miscarriage, articulated as a pregnancy that ends on its own, before 21 weeks' gestation (Births, Deaths, Marriages, and Relationships Registration Act, 2021). Additional inclusion criteria required participants to identify as a woman, be aged 18 or over, and to feel comfortable speaking and communicating in English. Ideally, participants would be located in Wellington, New Zealand, so that, if the participant desired, the interview could be conducted in person. Aware of how painful stories of miscarriage can be, care was needed to ensure that the women I spoke with were in as safe a place as possible to share their stories. I wanted women who became involved in the research to find the experience of participation beneficial, rather than cause them harm, particularly considering the identified lack of support after miscarriage that is evidenced in Chapter One. Aware that women with more recent experiences of loss may be particularly vulnerable to emotional distress, I consulted with Dr Vicki Culling to gain her insight into how I might ensure my inclusion criteria would promote emotional safety for participants. Dr Culling

shared with me that in her experience at Sands NZ, a national baby loss support organisation, bereaved parents are generally considered to be safe to begin supporting others when it had been 18-24 months since their most recent loss (personal communication, May 11, 2022). Therefore, participants needed to have experienced their most recent pregnancy or child loss (including ectopic pregnancy, miscarriage, stillbirth, or neonatal, infant or child death) at least two years prior. Discussing this criterion with a potential participant<sup>2</sup> during our initial meeting, she commented that she believed this inclusion was “a good thing”, and relayed that while participation may “bring up some stuff” for her, ultimately her distance from her experiences meant that she felt safe and eager to participate.

Aiming to gather rich, in-depth stories that spoke of the complexity, diversity and shared connections of experiences of miscarriage, I initially aimed to recruit eight to 12 women. While there are active and populous online support communities on social media for women and families who have experienced baby loss in Aotearoa New Zealand, I understood that advertising in these spaces may result in an influx of potential participants that would greatly exceed the time and resources I would need in order to do justice to the stories I would be told. Ethically, it was important to me that any interested and eager potential participants were given the opportunity to participate, as I wanted to avoid offering women an opportunity to tell their story and be heard, and then withdrawing that opportunity due to strained capacity. Therefore, participant recruitment was undertaken through asking intermediary contacts, women personally known to and trusted by me, to contact women known to them through their own personal social networks and who met inclusion criteria for the study and were not known to me. My hope for this recruitment strategy was that it would

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<sup>2</sup> The participant’s name has not been used, given this discussion occurred outside of the context of our interview, and participation had not yet been confirmed.

temper the flow of potential participants and harness and build on relationships of established trust.

Approaching women in my social circles as potential intermediary contacts, I was surprised that many women stated that they did not know anyone who had experienced miscarriage. To me this signalled the ‘hidden’ nature of miscarriage as, due to the common occurrence of miscarriage—approximately one in five pregnancies (McCarthy et al., 2020)—the likelihood is that these women *did* know women who had miscarried, and they were just not aware of it.

One woman I approached about being an intermediary contact expressed interest in participating. I explained that I had chosen not to recruit women known personally to me, a decision made to limit the risk of coercion and issues of power. She accepted this, yet days later asked if she could write some of her thoughts down for me anyway, as she had “some things to say”. Discussing this later with my supervisor, we mused over the possibility that *denying* this woman the opportunity to participate posed an ethical dilemma. We spoke together about whether any issues of power were present that might complicate the research relationship or our friendship, and we decided that given that this women really wanted to tell her story as part of the research, it would be unethical to suppress and silence her story, particularly as to do so would go against the very foundation of this research, which is to open spaces for women to tell their stories, breaking the silence, so that we may know how to grow our capacity for care for women who miscarry. Considering these points, and no issues of power being identified, the decision was made to invite this woman to participate.

Intermediary contacts provided potential participants with a hard copy or digital Information Sheet (see Appendix A), detailing in the aims and procedures of this research, in lay language, alongside inclusion criteria, participant rights and my contact details. Potential participants contacted me directly via phone or email to express their interest and a time for

an initial meeting was agreed upon. Initial meetings were held online via video-conferencing software (Zoom) or in person. To promote participant safety, convenience and comfort, potential participants who opted to meet in-person were asked to designate their preferred place for these to take place; all invited me into their homes. The initial meeting provided an opportunity to build rapport, establish trust, discuss limitations of confidentiality, determine cultural and convenience needs of participants, and to clarify any areas of uncertainty.

Buoyed by the guidance I was offered during cultural consultation, I sought to embrace manaakitanga and aroha to guide my research relationships with the women. My intention was to embody the expression of empathy, compassion and generosity, and to always uphold the dignity and respect of the women. It was important to me that engagement was meaningful and sincere, rather than an act of ‘doing rapport’ (Duncombe & Jessop, 2002) solely to incite participants to disclose emotions and experiences for the purpose of ‘data collection’.

Ultimately, six women participated in this research. Recruitment continued throughout the duration of my interview phase of research, and whilst I had initially planned to interview up to 12 women, each interview was very long (between 77 and 97 minutes), and the stories I was hearing were incredibly complex. I quickly realised that in order to undertake a thorough analysis that would honour each women’s story, given the scope of the project at hand, recruitment needed to cease at six participants.

All participants were provided a written informed consent prior to their interview (see Appendix B), and were afforded the right to withdraw their participation at any point up until the transcripts were released for analysis. Consent forms were stored in a secure location and separate to identifiable data. All participants agreed to their interview being digitally recorded and participants were informed that they could decline to answer any interview question or stop the interview at any time.

All participants were given grocery vouchers as koha to acknowledge participation, barring one participant for whom I donated the voucher on her behalf to a local charity at her request.

### *A Seventh Voice*

There was a seventh voice in this research: my own.

A holistic approach to reflexivity acknowledges the need to engage in reflexive practice across the entire research project (Hesse-Bibber & Piatelli, 2012). At all times I have strived to recognise and interrogate my role and perspective in this inquiry, understanding that what can be known within the boundaries of this research will be shaped and influenced by my own standpoint (Hesse-Bibber & Piatelli, 2012). My own positionality and presence is woven through this project, thus embedded within this research are traces of my story and my cultural, social and historical location. Therefore, it has been important for me to engage in constant reflexive practice to make explicit the way my own history, lived experience and social context informs this research. I have come to this research as a Pākehā, cis-gendered, married, middle-class woman, aware of the privilege I hold in many respects. I am also a mother to one young child and two babies who died during pregnancy, bringing with me knowledge, empathy and understanding of baby loss, and my own experiences of the silencing of miscarriage.

At the outset, before delving into literature or designing methodology, my first task was to write, freely and liberally, my own story, without any intention to publish this story, simply with the intention to begin this research with a telling. Telling my story is an acknowledgement of my standpoint and positionality, my role as a co-constructer and interpreter of knowledge in this research (Letherby, 2003), and also of me as a woman who has experienced miscarriage. Writing my story prompted the recollection of many forgotten experiences. I noticed how small details that might seem insignificant to others were vivid,

looming and painful to evoke. These ‘hot spots’ often took me by surprise with their sudden and sharp embodied feelings, and grew my awareness of parts of my story that were particularly meaningful or painful. I must admit that it took bravery to share my story with my supervisor in its raw and unrestrained form, yet to do so felt liberating because until that point it had not been heard in that fullness because there had been no space for it to be heard, so I had held it alone.

My story is woven through this thesis, notably in Chapter One, but also embedded throughout the body of this work and through the conversations with the women who participated. Telling my story is a way for me to come into, acknowledge and enact relationships between the participants, the reader, and myself, and the wider communities to which we belong. I have been taken by surprise by how bringing myself, my voice and my story into relationship with the women who participated led to expressions of mutual care, and in particular, I was surprised by the way the women cared for me. During one interview, a participant checked in to ask how listening to women’s stories had been for me, and asked whether I had my own support, should I need it. I assured her that I was well supported. She told me of the connection, care and support she had found at community support meetings, and urged me to ‘come along’ if I ever wanted to. During another interview, a woman (Tess) recounted a story uncannily similar to my own. She spoke about how in the wake of miscarriage her relationship with her best friend, who she had known since age three, had fractured deeply and that they no longer speak. I shared that this has happened for me too also, with my best friend since the age of three. She responded, “I really feel for you. I’m sorry that happened, because I kind of know exactly what that feels like”. This story within my story, that paralleled hers, is not easy for me to tell nor one I tell often. However, in the context of that relationship I shared it readily, comfortably and sincerely. Notably, the shame normally attached to that story for me was not present in that telling, and what emerged was a

feeling of being truly seen. My understanding of this sharing of mutual accounts of pain is that it did not inflate distress for either of us, but rather ignited compassion, care and deepened connection.

I have engaged in reflexive journaling practice for the duration of this project, documenting my emotional responses, uncomfortable and ambiguous thoughts and feelings, and musings over ethical tensions. Following interviews my reflexive diary entries noted emotional responses the women's stories evoked and elements of the interview that resonated, piqued curiosity or prompted discomfort. Frequent supervision with my research supervisor has also been a key element of my reflexive practice. These practices have helped me to ensure I can still hear my own 'voice' and have enabled me to interrogate how my own story has continued to influence my engagement.

### *Interviews*

Due to silencing and stigma, women are not often given opportunities to tell their stories of miscarriage. I was aware that while the opening of space to tell stories was embedded in ethics of care, relationships and empathetic connection, telling these stories can be painful and difficult. It was important to me that the women who participated felt prepared to speak within the interview context, had an understanding of what the interview would entail and had time to consider their responses in advance. One of the ways I sought to reduce any distress for participants was to provide an Interview Guide (see Appendix C) ahead of time and talk with the women prior to the formal interview. I also developed a comprehensive Participant Safety and Support Plan (see Appendix D), with particular emphasis on how care and participant safety would be promoted throughout the interview encounter. Furthermore, I also remained connected to the wider community of support, and with Dr Vicki Culling who, in an act of care toward my participants, offered to personally provide free one-on-one, face-to-face online support for any participants who desired it, at their request.

Individual interviews were held either face-to-face or over Zoom. Participants were invited to bring a support person(s) or whānau (who would be required to sign a confidentiality form, see Appendix E), however no participants chose to do so.

When invited into the women's homes I brought food to share, an act of manaakitanga (care, hospitality) that felt natural and meaningful for me as someone who will often bring food, drinks, flowers or gifts when invited to the homes of people I am in relationship with and want to show my care for. In return, the women showed care towards me by offering a hot drink and, in one instance, kindly insisting on cooking a meal for us to share together.

Prior to starting the interview I engaged in conversation with the women to reconnect and put them at ease. My intent was to foster research encounters that felt warm, non-judgmental and safe. I asked the women if they were feeling ok to proceed, answered any questions that had arisen since we last spoke, and we revisited the participant's rights and confirmed consent. I expressed that they could tell their story in the way that felt best for them, and that they could conceptualise the notion of social support in relation to miscarriage however they saw fit. I mentioned that I might share parts of my story too, and checked they felt ok with that.

All participants consented to having their interview recorded. In-person interviews were digitally audio-recorded, and Zoom interviews were also visually recorded and the visual recording file was destroyed immediately upon interview conclusion while the audio file was retained for transcription. Digital audio recordings were stored securely on a password-protected device, separate to identifiable data (consent forms) and were destroyed after transcription.

Beginning the interview, I simply asked the women to tell me their story of miscarriage and social support. I prioritised flexibility, allowing the interview to unfold

according to the needs and stories of the women. I endeavoured to create space for women to tell the elements of their stories that felt important to them, in particular allowing ample space for the women to texture their accounts, recognising that while on the surface the talk may not appear to relate directly to social support, the unique contexts and fabric of these women's lives rendered their stories and experiences meaningful. Furthermore, interview encounters relating to sensitive or silenced topics, such as miscarriage, can involve the telling of 'untold stories' (Dickson-Swift et al., 2007) thus it was important to me to open space where women felt like they could speak about anything they felt they wanted to.

Hydén (2008) posits that sensitive topics are relationally defined, and within this project I do note the interplay between the 'sensitive' nature of miscarriage and the shared standpoint of myself and the participants as women who have experienced miscarriage first hand. What I mean by this is that our shared knowledge and our shared desire to come together to speak of our experiences tempered sensitivity. Within these relationships and encounters there was space to speak about the pain, hurt, blood and mess of miscarriage, or challenging feelings about the pregnant women in our lives who are loved by us, without the degree of sensitivity demanded in our social spaces. At times the women expressed thoughts and feelings that they considered too harsh, or too upsetting, to share with others in their lives. Some of these thoughts and feelings I could recognise as my experience too, highlighting the importance of a non-judgmental space so that we may speak of things that we might usually silence but that we experience and feel deeply. Connection through these experiences can ease shame, and quell the unsettling fear of being 'abnormal' or wrong for thinking and feeling a certain way.

My responses to the stories of the women through the interview encounter were sincere and embodied. Exploring human lives requires facing human feelings (Dickson-Swift et al., 2007) and it felt important that rather than assuming neutrality and detachment, I met

the women's stories responsively and emotionally. The women were animated, expressive and emotive in their storytelling, and in response I conveyed my surprise, joy, sadness, curiosity, indignation and empathy, among other things. I opted to be present, to listen and to feel.

Reciprocal sharing of stories occurred through my conversations with the women. A feminist approach to interviewing woman prioritises non-hierarchical relationships whereby the researcher brings their own identity into the research relationship and process (Oakley, 1981). Sharing parts of my story enabled connection through finding commonalities and shared experiences, and indeed many instances where I shared my own story were when my experiences resembled the women's own. Self-disclosure by researchers has been touted as good practice by some feminist scholars for its capacity to minimise power differentials, enhance rapport, demonstrate respect for participants and validate participant accounts (Dickson-Swift et al., 2007). Indeed, it has been proposed that when women interview women they engage in a process of 'woman talk' through which knowledge and meaning are cooperatively constructed (DeVault, 1990). Interviews are fluid and dynamic encounters, where balances of power can shift within and between interview contexts (Cotterill, 1992). I believe my disclosures engendered understanding and comprehension from the women, but also disagreement and curiosity, demonstrated when the women verbalised a different view to mine or asked *me* probing questions. My interpretation is that these responses occurred within a relationship where trust and connection had been established, allowing for diverse connections and understandings that ultimately contributed richness to the conversations and generation of knowledge.

Interviews concluded when the women indicated they were ready to end the interview, or when the talk slowed and I asked if they wished to conclude. I ceased recording and debriefed with the women, asking how they were feeling and how the interview had felt

for them. Each time the conversation continued to flow with ease, and in some instances the women continued to speak of their miscarriage and social support experiences. On one occasion I turned the recorder back on, with the woman's permission, as she remembered something she had wanted to say.

To conclude, the women were invited to contact me if there was anything they wished to add to their account. Before departing I reminded participants of the support resources available to them, encouraged them to access them if desired, and to contact me if they wanted support to do so.

### ***Transcription***

Interview recordings were transcribed by me promptly after each interview to ensure the interview context could be easily recalled during transcription. I transcribed the recordings myself to increase my engagement with the stories and as an initial interpretative act.

I had invited the women to select a pseudonym or to let me choose one on their behalf. One woman originally suggested I use her real name, raising an ethical issue whereby I noted the tension between being in relationship with this woman, wishing to let her own her story and tell her story precisely how she wanted to tell it, and my obligation to protect participant anonymity and confidentiality within the institutional demands of university research and to protect the participant from any unintended consequences that could arise from identifying her in the study. After discussion with the woman we agreed it would do no harm to maintain confidentiality by giving her a pseudonym.

To preserve both confidentiality and the women's narratives, I sought to remove identifying details during transcription while retaining the essence of their stories. For example, more general identifiers replaced specific references to people's names, locations, or ages through the use of terminology such as "my friend", "pre-schooler" or "a city away

from home”. Transcripts were stored securely, separately from identifiable data and accessible by only me. Care was taken to ensure any passages or stories within a transcript that were deemed especially unique to that woman and therefore potentially identifiable were not explicitly referenced or presented in the analysis. My embeddedness in the baby loss community, and the numerous stories I have heard told in these spaces, have aided me in understanding what stories are common and would not identify women. I note that for those who have not heard many stories of miscarriage some of the stories or details may sound uncommon or unique, such as having seven miscarriages, or miscarrying in a work meeting; these things are not novel, rather the silencing of miscarriage stories shrouds their visibility.

Transcription can create space and freedom for researchers to respond emotionally to data (Dickson-Swift et al., 2007) and through my engagement during transcription I noticed myself being moved by the women’s accounts in new ways, deepening my understanding of their experiences. For example, initially I found one woman’s story to be particularly painful and sad, yet as I came to know her more intimately through repeated engagement with her story during transcription, I began to understand her formidable strength and bravery, and to see her as empowered.

Devault (1990) advocates for preserving women’s speech through transcription, arguing that the smoothing of respondents’ talk can work to distort women’s words and overlook elements of women’s experiences that are more challenging to express. As such, I chose to retain some of “the “messiness” of everyday talk” (Devault, 1990, p. 109), including laughter, intakes of breath, sighs, hesitations, repetition and instances of self-correction, to ensure that the meaning and emotionality embedded within these utterances was preserved. Furthermore, my own speech, as well as the women’s, was retained in the transcripts in recognition of the co-construction of the narratives through conversational interaction.

In the spirit of promoting the mana and autonomy of participants and to enhance trust and transparency within the research relationship, all participants were invited to review and edit their transcript. They were informed they could withdraw material should they not wish it to be included in the analysis or edit their contribution should they feel that doing so would allow a better representation of their experience. Authorisation for release of transcript (see Appendix F) was confirmed either at the time of the formal interview if women did not wish to review their transcript, or at the subsequent review meeting for those who did.

One woman chose to review her transcript, which was done with me in her home. She identified minor areas of content where she felt the specificity of some events described may compromise confidentiality; we agreed these areas would be deleted from the transcript and not used in the final analysis.

### *Analysis*

**The Listening Guide.** A Listening Guide Analysis involves three successive ‘listenings’ of a single transcript: Listening for the Plot; I Poems (“I” voice); and Listening for Contrapuntal Voices, allowing for a multi-layered and nuanced exploration of stories.

***Listening for The Plot.*** The first step of the Listening Guide involves listening for the plot. This requires mapping “the psychological terrain” (Gilligan, 2015, p. 71), becoming attuned to the narrator’s relational world. I engaged Gilligan and Eddy’s (2021) advice to attend to each woman’s story and take notes, aiming to be descriptive, to prioritise the woman’s words and language and to stay close to the woman’s story as expressed by her. The women’s stories, as told to me through our conversation, were expansive, complex and often nonlinear, and I found that listening for the plot helped to orient and familiarise me with each woman’s story, enabling me to begin to understand it as a whole and as a journey. I listened for “what is happening, when, where, with whom, and why” (Gilligan et al., 2003, p. 160) and for contradictions, metaphors, ruptures and absences in the narrative. While listening, the

researcher is urged to resist categorisation and interpretation, and instead lean into curiosity, attending to elements of the story that stand out for the listener—notable absences within the narrative, or areas that ‘glow’, seem out of place or engender an emotional response (Tolman & Head, 2021).

This first step of The Listening Guide also calls for the researcher to record a Reader Response. This is a conscious, attentive and reflexive process where the researcher locates themselves and their social location to the ‘hearing’ of each participant’s story (Gilligan et al., 2003). I noticed and noted my thoughts and feelings that emerged encounters with the women’s stories, in particular noting how or where I felt connection with or distance from the women, similarities and differences in social location, and my own ‘emotional hot spots’ that arose in response to their stories. This process helped bring awareness to how my own assumptions and responses might inform and shape the way I listened to, heard and interpreted the women’s stories.

My responses were recorded in written form and proved insightful for me. I have made an ethical decision not to document in this thesis my responses as connected to particular women and stories. To do so may compromise anonymity and may not uphold the dignity of my participants. My responses were unrestrained and personal, detailing the varying strength and quality of connection I felt with the women, the difference and distance that I noticed, and the challenges that their accounts sometimes raised for me, as well as detailed descriptions related to social location. Censoring my responses for presentation, knowing that my participants may read this work, would undermine the very purpose of the reader response.

I want to caveat this by saying: despite differences in social location, experience and understanding, overall I felt easy and strong connections with all of the women. Thus, this

processes has highlighted for me the possibility of connection through diversity and of being able to gain entry into the standpoint of another through connection.

*I Poems.* The aim of the second listening is to tune into the narrator’s voice to hear how they speak about and know themselves (Gilligan et al., 2003). This step involves listening for the “I”, the presence of the narrator within their story, through the creation of ‘I poems’. I poems are constructed by first identifying, and in my case underlining, every first-person “I” statement in the transcript, taking the “I”, the accompanying verb and any accompanying words deemed important. These ‘I statements’ are then placed in the order in which they appear in the text, each on a new line, to construct a poem. Stanza breaks occur where the ‘I’ shifts or takes a new direction (Gilligan & Eddy, 2021).

When I first encountered The Listening Guide it was the I poems that sparked my attention, as one participant had spoken of using poetry to express her experiences of miscarriage, and to invite other people into her experiences. Curious, I began creating I poems from the women’s stories. Immediately I noticed how often the women used “we” to describe experiences shared with their partners, and how focusing on the “I” enabled me to explore where, and why, a woman accounted more explicitly for herself. I poems drew out the women’s embodied experiences, both in terms of the physicality of miscarriage and their emotional responses. I also started to hear “I want” and “I need”, which struck me as particularly important in the context of this research that sought to privilege women’s lived experiences and to understand the care and support women want and need when their babies die. These notions are expressed in the following excerpt of Sara’s I poem.

I had a hand held

That’s what I needed

I needed someone

I was lucky

I couldn't move

I was biting on the mattress

I was on the floor

I was biting

I really thought I was in a medical emergency

I think

I knew

I was like, "*No. This is just a miscarriage*"

I'm just going to suffer.

We hear the raw physicality of Sara's experience as she's *on the floor, biting a mattress, unable to move*. We hear that *having a hand held, having someone*, was what she *needed*, but that she considered herself *lucky* to have those things, signalling that they are not the norm.

The theoretical assumption underpinning I poems is that they represent associative logic: knowledge that "runs under the surface of the narrative or exists outside the person's conscious awareness, and yet gives voice to what people may know about themselves without quite knowing that they know it" (Gilligan & Eddy, 2021, p. 148-149). Therefore, I poems are not intended to convey the story but rather to expose patterns of someone's associative logic. Consequently, (Gilligan & Eddy, 2021) attest that focusing on the "I" and the verb that follows is the most effective way to lay bare the associative logic, however in constructing the women's I poems I have often chosen to include additional words. Given that the

women's I poems, like their stories, are extensive, including additional words has helped orient me through analysis by enabling me to understand how a woman is accounting for herself within different parts of her larger story, allowing me to situate her in her journey as she speaks of herself. It has also helped me to hear how she speaks of and situates herself in relation to others. For example in Sara's I poem above, I included "someone" in the phrase "I needed someone". The addition of 'someone', rather than just the verb, tells me about Sara's need in relation to her social context. Furthermore, I have prioritised the inclusion of words that convey the women's embodied selves and experiences, feeling it important to honour the physicality of their embodied selves and experiences. For example, in Sara's I poem I included "I was biting on the mattress" instead of just "I was" to provide a sense of Sara 'being' in that moment of embodied action where she was in so much pain, biting on a mattress.

Although I have included more elements of the story than recommended or required, through repeated engagement I have also listened to each I poem in its pared back form, with the "I" and the following verb. In the second stanza in Sara's I poem, for example, I listen to Sara say: *I couldn't/I was/I was/I was/I really thought I was/I think/I knew/I'm*. I hear her locating herself as she *was* then moving through a process of thinking/thought to knowing, ultimately arriving to a state of embodied knowing.

***Listening for Contrapuntal Voices.*** This final listening is shaped by the research question, bringing it back into focus. Listening for contrapuntal voices involves identifying diverse voices speaking within the storyteller's expression of their experience, and listening for the interplay of these voices with one another (Gilligan & Eddy, 2017). The logic of this step is grounded in the notion of musical form counterpoint, thus the researcher is directed to listen to the quality or musicality of the storyteller's voice to identify the different voices that speak within the narrative (Gilligan et al., 2003).

Listening for contrapuntal voices was an iterative process. I listened for tone, language and movement. My transcription process involved listening to each recording three times and as such I retained a good sense of the quality of the sound of the women's voices across their stories, such as volume, emphasis, strength, pitch and pace. I remembered where their voices quavered, where they spoke rapidly, where the tone was gentle and where there was lightness and levity. Listening for these qualities, and using my research question as a touchstone (Gilligan & Eddy, 2017), I engaged with the women's voices until I started to hear particular voices speaking within the narratives. Coming to know a voice, I wrote down its markers (for example, pleading, questioning, soft, slow) and tracked and recorded its presence through the narrative. Following this, I pulled all instances of a particular voice from the transcript and placed them together in another document, in the order that they first appeared, so that I could listen to the voice in isolation, giving me a strong sense of what the voice 'was'. Finally, I named the voice, drawing on the woman's words where possible, for example, "The Voice of Connection", because Louise often spoke of connecting and connection, or "The Voice of the Wild Red Flag", a metaphor used by Joanna.

The Listening Guide approach is geared to curiosity and discovery, and I found that the iterative nature of the 'listening' led to many 'wow' moments for me—moments where I dropped into a new depth of engagement with the stories, or my relationships with the women expanded through listening. For example, looping back into a transcript to listen for contrapuntal voices after being heavily absorbed in the voice of the "I" renewed my engagement and opened space for deeper analysis. After intimately coming to know the women through listening to them account for themselves in their story, hearing them situated once again in multivocal ways in the context of their stories highlighted the diverse and complex ways that they related to others and were related to, and ultimately what that meant for how they experienced social support during and after their miscarriage.

**Composing an Analysis.** The final step of The Listening Guide involves drawing together the knowledge gained through each of the listenings to compose an analysis. By this point my transcripts showed traces of my successive listenings, with I Statements highlighted, and two or three contrapuntal voices identified using bold, underlined or italic text. From here I explored the way the different voices—the I Voice and the contrapuntal voices—spoke to, with or apart from each other through the narrative, providing a deeper engagement with each story and the women’s experiences within it.

**Bringing the Women Together to Speak.** I have taken an additional analytical step not included in the Listening Guide, derived from my own experiential journey through analysis. Through my engagement I began to hear the women ‘speak together’. Listening deeply to a woman’s voice and her story, the voices of the other women would flash into my awareness, as if the women were speaking with each other, as well as speaking with me, and me with them. At first this occurred usually when the women spoke of similar experiences or concerns. For instance, listening to four of the women recount experiences of the gynaecological department waiting room, I began to hear their accounts as a conversation. Tess would say, “You know you’re sitting there thinking, oh my goodness, I’ve lost my baby”, and Joanna would reply, “And nobody knows why you’re sitting there crying”. I could picture the women sitting together, voicing their stories in relationship. I was there too, because I have my own story of being in that waiting room. Other times, I heard the women’s voices speak to each other in more complex and discordant ways, demonstrating the importance of hearing their unique standpoints, and opening spaces to explore complexity and diversity.

Listening to the women ‘speak together’ offered deeper engagement through my analysis, so I decided to more explicitly draw the women into conversation together, in written form, to see what they were saying with each other and collectively. I found these

‘conversations’ to be powerful and expressive, and in particular, to speak to the wider social order, and to how miscarriage and social support is experienced collectively and diversely, in an expression of a collective standpoint. Furthermore, hearing the women “speak together” moved me. Knowing that the silencing of miscarriage can suppress the occurrence of these conversations in real world settings, bringing the women together to speak is an act that signals possibility, an imagining of what we can come to know by allowing space for these conversations to occur. Through adding this extra layer of analysis, I am saying ‘let us hear women speak together and let us hear what they are telling us’.

**Storying the Stories.** In the following chapters I will present the women’s stories, and a discussion of my analysis of and engagement with their stories.

Some of the women spent hours talking with me, however due to the scope of this thesis, and the complex, multi-layered, and expansive nature of the stories, it has not been possible for me to open a space to explore every single aspect of the women’s stories that they shared with me, or to present here every detail that I have explored. I have been troubled by this, because the women’s stories are important, and it is important that they be heard. However, what I can be assured of is that I listened, deeply, to the women, and have endeavoured to honour their stories through my telling. My hope is that the elements of the women’s stories that I have chosen to present will allow the reader to feel as though they can come to know each woman, and come into relationship with her through the telling and listening.

In Chapter Three, each of the six women will be introduced, her story told and her voice heard through a recounting of The Plot, the expression of I poems (drawn from her full I poem), and articulation of her Contrapuntal Voices.

In Chapter Four I have brought the women together to speak in chorus, and at times I speak with them. My hope is that through listening to the women speak together, the reader

might also 'see' the women together, sitting together, perhaps, talking together, connected and responsive with one another. An imagining of possibility, of how opening space for women to speak and to speak together can enable us to hear complexity and diversity, complicate what we know, and grow our understandings of what it means to support women whose babies die during pregnancy.

## Chapter Three: The Women's Stories

### Joanna's Story

#### *The Plot*

When Joanna and her husband first decided to try for a baby, she knew she would be “up against it” due to her age and low egg reserves. Unable to conceive naturally, Joanna underwent in vitro fertilisation (IVF) and was overjoyed to become pregnant. Her pregnancy was closely monitored by the fertility clinic, who warned her not to get ‘too attached’ as her hormone levels were not rising as expected. However, Joanna remained hopeful. Sadly, at an early ultrasound, she found out her baby had died. She chose to miscarry at home, where she felt safe and comfortable, taking medication to aid the miscarriage process. Without being carefully informed of all the possibilities of the process, she returned to work believing the miscarriage to be complete. To her shock, during an important work meeting at another office she continued to miscarry, bleeding heavily on her chair. She was mortified that this had occurred in public, and that someone had to clean it up.

At the time of her miscarriage, Joanna received no psychological support from the fertility clinic or her doctor. She withdrew from family and friends. However, she was determined to keep trying for a baby. Disappointingly, her second round of IVF was unsuccessful. In a bid to “give it everything”, she quit her job to pursue one final round of IVF. To Joanna's joy, she became pregnant. After an easy pregnancy, she gave birth<sup>3</sup> to a living baby boy.

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<sup>3</sup> When I first wrote the women's plots, I would often simply say that they “gave birth to a son/daughter” without specifying that the baby was born living. However, on reflection, I began to see how such statements relied on assumptions of what we socially accept to mean ‘giving birth to’ and ‘a baby’ that denied women who miscarry the ability to have acknowledged that they, too, have given birth (in diverse forms) to sons and daughters that were no longer living at the time of that birth. I did not feel comfortable contributing to the reproduction of narratives and constructions that deny women's experiences of pregnancy, birth and motherhood in the context of miscarriage, so have chosen to have specifically articulate when children are born living in an act of accountability and resistance.

Joanna's first year of motherhood was tough, as she battled colic, sleep deprivation, postnatal depression and anxiety. Joanna tried to reach out for help, but she struggled to access support. Her husband increasingly became distant, and, when their son was one year old, he decided to end the marriage.

Joanna, now in her forties and sharing care of her child with her ex-husband, reflects on the miscarriage as being the catalyst for her emotional distress and family breakdown. Her story is one of coming to terms with life unfolding in a way that was unexpected—deviating from the story of a secure and loving marriage, easy pregnancy and joyful motherhood that she had hoped for.

### ***I Poems***

Early in Joanna's I poem I heard how Joanna once held herself responsible for her infertility, and for the success of her relationship, which she felt rested on her ability to have a child.

#### **Infertility**

I used to believe

I couldn't love a child enough

I'd made

I was in my late 30's

I was already quite advanced

I had found out

I knew

I was up against it

I thought my relationship would fall over  
 if I couldn't have a kid

Joanna once believed that her struggle to conceive was due to not being able to love a child enough. Such a belief positions Joanna as not worthy of motherhood and undeserving of a child. She claims responsibility for her infertility through recounting her 'advanced' age. The last stanza speaks to the sense of responsibility she felt to her husband and for the stability of her marriage, which she believed hinged on her fertile ability—as a woman, she knew she was expected to produce children, and she believed herself to be solely responsible for her struggle and her pain.

Moving through Joanna's I poem I heard her tenacity as she navigated fertility treatment and early pregnancy. The following I poem conveys Joanna's desperation to be, and stay, pregnant, despite being told that her baby had a 2% chance of surviving early pregnancy.

### **I totally clung**

I remember saying, "What are the chances?"

I said, you know, "What's the chances?"

I totally clung

I was determined

I carried on

I carried on

I was still pregnant

As Joanna's I Poem journeyed through pregnancy to miscarriage, I heard expressions of disbelief. Both disbelief that she was miscarrying, and disbelief that her emotional pain went unacknowledged and unattended within the medical system. In the following I poem Joanna conveys disbelief as she reflects on being in the gynaecology waiting room, surrounded by pregnant women as she miscarried.

### **Waiting Room**

I couldn't believe

I could not believe it

I had to wait

I can't believe that they do that

Joanna's astonishment at being put in that room is palpable. She was incredibly pained and dismayed to be treated like only a medical body with such little care for her emotional wellbeing. Her voice returns to present in the final line, suggesting that a decade later she is *still* aghast that she, and women like her, are forced to sit in waiting rooms with pregnant woman while miscarrying in our medical system.

Joanna's I Poem conveyed a sense of Joanna feeling unarmed and unprepared for the path she found her on (*I knew almost nothing, I went very blindly, I had no idea*). Her journey of family, pregnancy, motherhood and marriage was jarringly disparate from what she had hoped for. Eventually, Joanna "fell apart".

### **Falling Apart**

I was falling apart

I would be lying there

I'd be lying there

I was in [my son's] room

I was like, "Why are you not checking in on me?"

I mean

I can't say

I would just be walking around

I remember

I was walking

I remember

I had no idea what was going on

Joanna wonders why her husband cannot see her pain and desperation (*Why are you not checking in on me?*). She aimlessly walks around her home, losing her sense of herself and of reality. Her experience of being treated with so little care by her husband and by the system designed to care for her, and her displacement from expectations of motherhood, femininity and 'family', ultimately left her feeling desperately lost, not knowing how to journey through the unexpected, or whether she would be ok.

### ***Contrapuntal Voices***

**The Voice of Disbelief.** This voice had a tone of incredulity, using repeated phrases and descriptive imagery as if to invite the listener to 'stand in her shoes' and vividly

experience what she had experienced. It spoke to shock and surprise. Early in Joanna's story this voice precisely recounted Joanna's experience of miscarrying at work:

*There on a bright green chair, in a meeting room, in another agency, I miscarried. And it was—there was blood everywhere. And so I sat there, and the meeting finished, but the woman who was chairing the meeting wanted to talk to me. And I got up and I pushed in that chair and it was totally ruined. Like, I don't think blood made it onto the floor but I wouldn't know. And it was like a green, a lime green chair (laughs) ... And the cleaners had to deal with it. Somebody dealt with it. And I don't know who that person was. I feel really sorry for them. 'Cause I couldn't tell anybody what was happening. And there were A3 pieces of paper in the bundle and I held these pieces of paper around me and got out as quickly as I could. And then I had to just go back to my own office, because I didn't have my house keys on me. ... I just went home and bawled my eyes out. Could not believe this thing had happened.*

Navigating such a devastating and unfamiliar embodied experience in an environment that was usually safe, comfortable and predictable, and a place where she was “reasonably senior”, self-assured and professional, was shocking for Joanna. Notably, she felt that she “couldn't tell anybody what was happening”. We can ponder why that might be, why she felt that she had to hide. Had a person in that room bled in the same way due to reasons other than a miscarriage, would they hide and flee? Would they feel that they must stay silent?

The Voice of Disbelief also spoke to the way medical ‘care’ was insufficient, harmful and limited to Joanna's physical body. Her emotional needs were overlooked, such as when fertility services providers suggested another round of IVF very quickly after her miscarriage.

*I'm kind of surprised now that—well I went very blindly into the next round of IVF. And I'm really surprised that they kind of didn't say, hey hold up? You could do with a break after this. 'Cause I was a mess.*

Joanna was encouraged to pursue another pregnancy with no acknowledgement of, or support for, her emotional wellbeing. When women's bodies are medicalised, and seen as the means for fulfilling the social expectation to bear living children and achieve motherhood (Lupton, 2012), the focus is on the body's reproductive potential. Rather than responding to Joanna as a mother who had lost a baby, 'care' was limited to the physical body as Joanna was ushered towards another pregnancy, and fulfilment of the motherhood role.

The Voice of Disbelief also spoke to a breakdown of Joanna's expectations of a normative pathway of family-building and marriage. Joanna had once believed a child to be necessary for the success of her relationship. Speaking from her present perspective, the Voice of Disbelief expressed how in actuality, the relationship broke down "because we had a kid". Similarly, I heard Joanna's surprise that her husband left shortly after their baby arrived, a gross deviation of the norm where a married couple have a longed-for baby, parent and cohabitate happily together. All that she had held to be 'true' in terms of her life pathway was shown to be a fiction. She had finally 'got it all' after so much pain, effort and sacrifice, and it still was not enough to maintain the family unit.

Similarly, the Voice of Disbelief spoke to Joanna's expectations of motherhood being dismantled, following the birth of her baby. She recounted a casual encounter with a man from her infertility network.

*I said, "You know it's not what we thought it was, having a child. It's not what we thought it was. It's not good. It's not a good thing. It's not what we thought it was."*  
*(laughs) ... It was this, this terrible world that I'd entered into that I couldn't get back from. I think a lot of women must have that sensation of, it's a world that you've entered into that you didn't really choose. ... At the same time like there was never a second at which I did not, would not, have done anything in the world for [my child].*

Joanna's Voice of Disbelief speaks to the shattering of neoliberal principles of modern motherhood whereby 'good' mothers are happy, grateful, proud, and consider motherhood to be 'the happiest time of their life' (Kruse, 2023). Joanna loved her son deeply, and would have done *anything* for him, yet the realities of motherhood were shocking, painful and overwhelming. Joanna's story had diverged sharply from the expectations she had held for marriage, pregnancy and motherhood, leaving her in disbelief that her life could unfold in such a way. However, what Joanna experienced *is* common and *is* often the norm. Many women experience miscarriage (Quenby et al., 2021), postnatal distress (Obrochta et al., 2020), relationship tension and breakdown (Delicate et al., 2018) and ambivalence (Chapman & Gubi, 2022; Huppertz, 2018) in motherhood. Yet these were experienced by Joanna as *against* the norm to the extent that she felt overwhelmingly blindsided, disoriented and lost when her experiences countered the 'norm'.

**The Voice of the Wild Red Flag.** The Voice of the Wild Red Flag had an urging tone, reflecting on what occurred with clarity and wisdom to tell what *should* have happened and how things *should* have been. Looking back with hindsight, this voice detailed Joanna's experiences of 'severe' pain and suffering, and how those around her who were in a position to offer support did not see her distress, or if they did see it, chose to turn away from her.

*When I look backwards there are some things about the journey of infertility, particularly including miscarriage, that are clear red flags. That a whole range of different supports should be put in place. So, I had an obstetrician, so no midwife. So I don't know, a midwife probably would've picked up a lot more about what was going on. But the obstetrician, I should've been a wild red flag. Like, the degree of what was going on, it was quite severe.*

Within the clinical environment of fertility treatment, Joanna's distress was 'unseen'. Joanna told of repeated missed opportunities for support and care, including by her GP,

maternal and community mental health services, and antenatal classes. The limited emotional care Joanna *did* receive was postnatal counselling with a student, and “I was out of her league, I would say”. When miscarriage is not seen to be a priority in the medical system and care is provided by junior healthcare professionals (Yang et al., 2022) women experiencing miscarriage may feel that what they are going through is seen as unimportant. Assigning a counsellor in training when Joanna was a “wild red flag” might have signalled to her that her distress was not taken seriously, not considered severe, and unworthy of care from a more experienced professional.

At home, Joanna’s husband chose to look away, attending to his own needs with little regard for Joanna’s struggle through her early days of motherhood.

*[He] didn't participate in the nights. He still went to the gym, you know. Anyway. I was falling apart. He even stopped coming in to check on me in the night. I would be lying there, tears streaming down my face. Desperately hunting for rock bottom. Because in my life to date once you've found rock bottom you know, things got better. But this, there was no rock bottom. It just kept on getting worse.*

Joanna was unseen and overlooked so often that she began to feel invisible, losing her ability to see herself and to feel real.

*I would just be walking around the house—I remember I was walking round, like totally naked. There was milk everywhere. And I remember my mum coming and just shutting the curtains, 'cause the building site was seriously right there. But I had no idea what was going on.*

Hearing The Voice of the Wild Red Flag, Joanna’s inner strength became glaringly obvious to me. To be “desperately hunting for rock bottom” while in the depths of her lonely struggle shows Joanna’s ability to grasp on to hope. I had a sense of this voice becoming louder and stronger as Joanna’s story unfolded, in a cry to be seen. I realised this voice not

only cried to be seen *then*, but speaks from the present, holding everyone who *should have seen Joanna* to account. Joanna no longer holds herself accountable for her infertility, her miscarriage, her marriage breakdown and her pain. Now, she calls for social accountability, levelling a challenge at her social and medical community for not meeting her needs, and holding them to account for their lack of nurturant care and compassion.

The voices of Disbelief and the Wild Red Flag converge to tell a story of pregnancy and motherhood that deviates from the norm, speaking together from the present as a reckoning and a movement towards Joanna's unwillingness to shoulder complete responsibility for her own pain and despair anymore—responsibility Joanna can now see should never have been hers to shoulder alone in the first place. When Joanna expresses disbelief that people could turn away from her, she shows us how her wild red flag fluttered so rapidly and brightly and should not have gone unnoticed, forcing us to think about our own accountability when we 'see' and support (or fail to see and support) women after miscarriage.

## **Tess' Story**

### ***The Plot***

Unlike Joanna, Tess did not struggle with fertility issues, but instead “staying pregnant was more of an issue.” Her first miscarriage was so traumatic that Tess said it left an “indelible mark” on her, even in present day. After the shock of noticing bleeding early in her pregnancy one Friday, Tess, scared for her baby, rushed to the after-hours medical centre for urgent medical care. However, instead of 'care', she endured a painful physical examination by a doctor who mistakenly used hand sanitizer instead of medical lubricant and who sent her home to wait, frightened and worried, over the weekend until she could be seen at the hospital the following Monday.

Many miscarriages followed after this first ‘indelible mark’, but it wasn’t until a pregnancy with twins—a rare and risky type of twin pregnancy with a poor prognosis—that Tess began to lose faith and hope: a loss that was the result of the medical professions’ inability to honour and acknowledge her love and hope for her babies, who were still alive within her body. Because her babies were not viable the fertility consultant did not consider them to ‘exist’, resulting in a complete disregard for Tess’ experiences as a mother and for the enduring bond between a mother and her children. Instead, Tess was viewed only as the carrier of an incompatible pregnancy.

*I remember having this really emotional conversation with this fertility consultant, and I remember getting really—I won’t say angry but it was definitely an emotionally-fuelled conversation. And I remember saying to him, “Look, I know the babies aren’t going to make it, but can’t you at least just let me celebrate that we’ve created this, you know, amazing thing, and ok it’s not going to last, but something special happened here, and can you not let me just have that?” And... he couldn’t.*

Tess was never able to fulfil that role of (normative) motherhood by having any living children. She feels that miscarriage undermined her sense of having control over her life, resulting in the abandonment of neoliberal assumptions that if we shoulder responsibility, and work hard, we will be successful and get what we want. “[It] did rob me of that innocence, that feeling that, you know, I had control over everything in my life, and that if I wanted something I could go and get it”.

Now in her forties, still happily married, Tess feels that over time she has come to terms with how her life has unfolded. Today she feels settled and content. However, she acknowledges that this contentment may be temporary. When looking towards her future, she expects her miscarriage grief to reappear when she encounters new life events and stages. As

she moves toward older age as a mother with no living children, Tess is now reflecting on her purpose and her contribution to the world, carrying her grief with her as she goes.

*What is my proper purpose in life and what is the legacy that I want to leave on this planet? I'm going to have to be a whole lot more creative because I'm not going to be able to pick the easy option and say well, you know, I've raised 3 beautiful children. That's not my legacy. It needs to be something different. So that's a form of pressure ultimately, that the miscarriages caused as well.*

Tess knows her grief will return, but she faces her future head-on with a commitment to creativity, open to possibility as she imagines a different future. Her future may not look like the normative mothers' future, and while she may have work 'harder' and more creatively, she is beginning to imagine how she can understand her legacy without the presence of living children.

### ***I Poems***

Often hearing *I reflect, I was, I remember, I've seen*, and frequently, *I think* through Tess' I Poem, I had a sense of Tess looking back to her experiences with significant distance, recalling and reflecting on how the events of her miscarriages unfolded and how she experienced supportive and unsupportive social encounters. However, at times she shifted into present tense, recalling embodied experiences, like sitting in the gynaecology waiting room surrounded by pregnant women.

### **What The Hell**

I don't know if they've changed this

I mean what the hell

*I've lost my baby*

*I'm losing my baby*

I wrote to them afterwards

In the second stanza I hear Tess 'becoming' a miscarrying woman again when she is 'losing' her baby. Locating her present self back in that moment through embodied feeling and knowing, her pain and anguish here is not only a remembering of an emotional experience in the past but becomes accessible and present right now. While Tess has 'distance' from her experiences, they continue to move through her. I hear Tess' strength as she condemns the care she received, spurred to advocate for systemic change not only for herself, but for other women like her. This tone of strength was frequently evident in her I poems, often arising after tentative statements where she was less sure in her 'knowing', such as in the following I poem where she discusses early pregnancy disclosure.

### **12 Week Rule**

I can kind of understand

I've seen it from both sides

I still don't quite know

I think on one hand

I still don't know

I think

if I had to make a call

I actually think

I think

I think the feelings of shame would disappear

Tess moves from uncertainty and hesitancy as she weighs dual perspectives of whether or not to speak of pregnancy before 12 weeks gleaned from ‘seeing it from both sides’ and expresses that she doesn’t “quite know”, before swiftly landing in certainty: *I actually think*. Her assertive, assured tone affirms my experience of Tess as a woman of wisdom, forged through experience: one who holds experiential and embodied knowledge that needs to be heard in order to better support women during and after miscarriage. The following I poem, speaking to grief, again shows Tess’ strength and wisdom.

### **I Know**

I’m older now

I know what grief looks like

I’ve had too much grief

I know what grief looks like

I think most of all

I think for women knowing

*this is a grief*

*that is going to be with them.*

This I poem conveys Tess' clarity and confidence, speaking from the present as a woman who intimately knows grief. She acknowledges and validates the existence of enduring grief for miscarriage—a grief seldom recognised by the medical profession, or socially (Frost et al., 2007; Lang et al., 2011; Rowlands & Lee, 2010). Tess *knows* grief, and she *knows* that grief continues to move within her, shaping her life in diverse ways. she advocates for the acknowledgment of knowing that “this is grief” and that the grief is “going to be with them” in order to better care for and support women who miscarry.

### ***Contrapuntal Voices***

**The Voice of Invisible Grief.** This voice was sorrowful and tender. It spoke to being unseen and unacknowledged while grieving.

*It just becomes this kind of grief that's... it's invisible. It's an invisible kind of grief where you're in tremendous pain but actually the services around you, the people around you, they make light of it from the point of view that it's just not really taken for what it is.*

The Voice of Invisible Grief spoke to being unseen in grief and unseen in motherhood, without any living children to legitimise Tess' identity of 'mother' socially. This voice told of Tess' risky twin pregnancy and how healthcare providers refused to acknowledge the meaningfulness of the experience for Tess and her husband.

*I just wanted some way of being able to acknowledge that something had happened. To be able to acknowledge that there were two lives, they counted, they meant something, they weren't just a petri dish to us. And I needed some way of being able to acknowledge their part in my life. And look, they just couldn't, they couldn't get their head around it, they didn't know how to support us.*

Under the medial gaze the emotional experience is discarded and deemed unimportant. Working only with the physical body, the medical system is poorly equipped to

respond to emotional aspects of the miscarriage experience, yet this is what Tess, and many other women, so desperately need. Speaking to love and pain, *The Voice of Invisible Grief* was that of a mother cherishing her babies during the short time they lived within her, pleading to be understood as a loving mother, yet being dismissed and discounted.

Tess spoke of how ‘invisible grief’ can give rise to lasting emotional distress.

*The secrecy that surrounds miscarriage, the fact that we shut it away like it’s some dirty secret that we have to cover up. All it actually does is get people to push that trauma or grief down and inside to an area deep inside us, that it’s not processed from a mental health point of view. ... And that’s not a way to deal with trauma. And it’ll pop out at some point, later in life.*

When grief is not acknowledged, or seen to exist, women are denied opportunities to work through that grief and to be supported as they do so, increasing their vulnerability to distress.

**The Knowing Voice.** This voice had a tone of certainty and purposefulness. Grounded and wise, it spoke from Tess’ present-day awareness, reflecting on what she has learned through experiencing miscarriage. This voice of knowing holds the complexity and contradiction that accompanies women’s experiences of miscarriage, where both contentment and wariness can co-exist; where ambivalence is ‘normal’ and should be acknowledged in order to care for and support women throughout their lives after miscarriage.

*I’m in this period of my life when I’m really—I’m settled and content with the fact that ok, we gave this family building thing a go. It didn’t work out, we had some tragedy along the way. We couldn’t have expected more from us than we already had done. But I know that there will come another time in my life, it’s probably actually not that far away, where the miscarriage and the grief is going to rear its head again.*

Tess is *certain* that she *must be wary*. She knows grief does not resolve, and she knows that she is content now despite the grief she carries with her. While her grief may be invisible to others, and may not cause her pain today, she still holds it inside, continuing to feel it and meet it in new forms as she journeys through her life.

*My retirement existence is never going to be grandkids coming round, you know, for lollies and granny's baking. But I think in the back of my mind I know that I still need to mentally prepare for the fact that actually the grief around my miscarriages is going to rear its head again in a really ugly way and I suspect that it'll probably be around that next change of life.*

The Knowing Voice is vigilant and self-protective, yet strong. Tess will not be denied her grief, not will she 'shut it away' or 'push it down'. She will prepare now and meet it when it comes.

## **Sara's Story**

### ***The Plot***

Sara became pregnant for the first time not long after moving to New Zealand. While Sara's husband had a child from a previous relationship, this would be their first child together, and they were excited. When Sara's morning sickness wore off after six weeks, she told her neighbour how wonderful it felt to no longer feel nauseous. The neighbour gave her a funny look, but said nothing. Sara was left to wonder if something had gone unsaid. Two weeks later, in a café bathroom, Sara noticed she was bleeding. An ultrasound confirmed that sadly, her baby had died. While healthcare providers gave her medication to aid her body to pass the baby, Sara's sadness and grief went unacknowledged. As Sara had told few people she was pregnant, and because she had few friends in New Zealand, she largely coped with her feelings of sadness alone.

Sara became pregnant again, and gave birth to a living baby daughter. She hoped for a living sibling for her daughter, and was delighted to become pregnant again when her daughter was a toddler. One day, while home with her daughter and stepson, she began to bleed. Gripped by agonising pain, she called a friend, who stayed on the phone with her, guiding Sara through her pain and distress. Despite having miscarried before, Sara had not expected to miscarry a second time, and she experienced intense grief. By this point, Sara's social network in New Zealand had grown. She was able to share her experience with her antenatal group friends, who made her feel cared for. Sara noticed, however, that no one else from the group ever disclosed personal experience of miscarriage, surprising her, as she knew how frequently miscarriage occurs.

Sara became pregnant again, and had another living child. All four of the children she carried inside her womb—two living, two lost to miscarriage—are depicted in a tattoo on her arm. Today, Sara works in women's health. Normalising grief is important to her, and she is passionate about increasing access to care and support for women and mothers experiencing mental distress.

### ***I Poems***

Creating Sara's I Poem, I noticed how she positioned herself as 'not knowing', as someone who had learned, and as someone who knows. I had a sense of her having been on a journey of discovery. The following I poem expresses Sara's movement through a journey of coming-to-know.

#### **I Had A Hand Held**

I am so glad

I learned to tell

I was pregnant

I was in utter agony

I had my toddler with me

I was distressed

I had a little lie down

I was writhing in pain

I was miscarrying

I was on the phone

I said

I had to

*“I’m having painful miscarriage*

*I need to go away”*

I can hear

I was on the phone

I said

I was like... phwoar!

Had I not told her

Would I have had that?

Would I have been able

Who would I have called?

I would’ve gone through it all by myself

I don't know

I didn't call him

I'm trying to think

Did I call him?

I think I called him

I must've

I must've

I said, "Is this what labour's like?"

I'd had a caesarean

I said, "Is this what labour's like?"

I had a hand held

That's what I needed

I needed someone

I was lucky

I couldn't move

I was biting on the mattress

I was on the floor

I was biting

I really thought

I was in a medical emergency

I think

I knew

I was like, “*No. This is just a miscarriage*”

I’m just going to suffer.

This I poem expresses Sara’s journey through her second miscarriage. Her evocative language in the second stanza conveys an intense and painful embodied experience (*I was in utter agony, I was distressed, I was writhing in pain, I was miscarrying*). I hear Sara coming to know miscarriage through experiencing it with and in her own body, moving from a place of distress, uncertainty and confusion to ‘knowing’ what was happening within her body. I notice how she slips into present tense to describe her past experience (*I can hear*), giving a sense that she is vividly reliving that embodied moment.

In the fourth stanza Sara questions who she could have turned to for support, had her friend not been on the phone, realising that had her friend had not been there, she would have “gone through it” alone. The silencing of miscarriage can limit pathways to care, where women are uncertain who, if anyone, they can turn to when experiencing the pain and distress of miscarriage. Sara *needed* support (*I needed someone*), yet situates herself as ‘lucky’ to receive the support she needed, implying that good support is not something that everyone has the ‘luck’ to receive. Sara, and other women experiencing miscarriage, should not feel ‘lucky’ to receive support when navigating such heartbreak and trauma, rather, it should be normal and expected to be supported and cared for through miscarriage.

The final stanza conveys Sara’s transition from tentative embodied awareness, knowing that something was happening, but not being able to name what it was, to legitimising her own embodied wisdom and knowledge: *I think, I knew*. Trusting in her body and in her understanding of her body, she accepted that her pain and her suffering was the result of the experience of being a woman who is miscarrying their baby. Why is it that this

level of suffering is accepted in the context of miscarriage? Would suffering of this magnitude be expected to simply be endured, with no support or care, if it was due to an illness or another condition? When miscarriage is silenced and normalised as insignificant, then women accept this level of suffering as just par for the course.

### *Contrapuntal Voices*

**The Voice of Unknowing.** This voice was hesitant and uncertain, yet it did not sound awkward, or embarrassed, that it did not ‘know’. Rather, it was motivated to understand. It frequently took on a questioning tone, scrutinizing the silencing around miscarriage and how silence might hinder support.

Sara’s story started from a place of unknowing. Experiencing miscarriage for the first time, she did not understand what was happening to her. This voice spoke of Sara telling her neighbour that her morning sickness had eased: “But she didn’t say anything to me, and I just left with this, *why did your face do that funny weird thing?*”. Sara reflects, in hindsight, that her neighbour’s facial expression was because her neighbour knew something was wrong, but what the neighbour ‘knew’ went untold. The silence around miscarriage means that even the *possibility* of miscarriage stays unspoken. Sara was left alone in her unknowing, unable to learn from the wisdom and experience of her community.

The Voice of Unknowing spoke to Sara feeling ‘lost’ as she experienced the grief of miscarriage for the first time. Briefly slipping into present tense, I heard how despite now having living children and having experienced normalised ‘motherhood’, Sara’s feeling of being ‘lost’ was so intense that she relived it again through her reflections.

*I’m just lost, I haven’t experienced motherhood. I haven’t experienced, you know... you can grieve at losing someone external to yourself. But the grief of losing someone you were creating. And the future that was mapped out for like the next 50 years is*

*suddenly a different path. It's like, all of that grief, you can't explain. So it's just back to normal! You're fine to go back to work. And life cruelly continues...*

Sara was unsure how to hold, and be with, this new sort of grief—a grief specific to losing a baby. Looking to a different future, Sara moved onward holding her grief and her painful experiences of miscarriage that were unseen, unacknowledged and unrecognised others. The notion that life ‘cruelly’ continues portrays a sense of unfairness and resistance to the lack of acknowledgement from the world around her.

The Voice of Unknowing was also present during my conversation with Sara, as she repeatedly questioned whether the word *miscarriage* is appropriate. “Just even saying the word again, like... where does the word ‘miscarriage’ come from? Is it like... is that the right word to use? ... It sort of means like, I’m carrying it, and I’ve made a mistake!” She mused over how it may place blame on women, wondering if there might be a better term to “depersonalise it from the mother’s fault”. Sara’s ponderings speak to how women can feel responsible for the death of their baby through their personal individual failure to ‘carry’ their baby correctly. Such feelings of responsibility can produce shame and self-blame for women when their baby dies during pregnancy, and in turn, can mean women are left alone to hold shame, and grief, alone. Sara explicitly resists the construction of women, and their bodies, as responsible for miscarriage, challenging assumptions that provide the conditions for shame and self-blame through imagining how we might speak differently about miscarriage in ways that do not hold women accountable for the death of their baby.

**The Seeking Voice.** This voice was lively, upbeat and often exacerbated in tone. It spoke to Sara trying to move from a place of unknowing as she sought knowledge and understanding about what was happening to her and to her baby.

I had assumed that The Seeking Voice would lead to, and perhaps be synonymous with, coming-to-know. Surprisingly, however, it often looped back to *unknowing*. The

process of becoming informed about miscarriage was rife with confusing and conflicting information and misinformation. As such, The Seeking Voice overlapped with The Voice of Unknowing as Sara struggled to make sense of her experiences.

*There was nothing actually concise and available and it was all through Facebook or messages or groups... you just turn to other people and you just get such a mix of stuff that you really don't... I really didn't know what was true.*

Turning online, due to the silencing of miscarriage limiting opportunities for face to face support, Sara was met with unreliable and conflicting information, leaving her *more* confused, and more distressed. The cacophony of the voices of strangers online, saying many different things, made it hard to trust any information provided.

Within Seeking Voice I heard humility, levity and lightness, too. Sara recounted that she should have 'known better' when recounting a "horrible memory" of making a joke with a woman she knew about the large number of children the woman had, not realising the woman had suffered multiple miscarriages. While Sara held herself to account for her insensitivity, she reflected that her careless joke emerged from broader social norms and processes, "because we just rely on the stuff that we were brought up with. The language that our parents gave to us." Here, Sara is aware of how the silencing of miscarriage constrains our ability to consider that other women, regardless of whether or not they have children and how many, have gone through the trauma of miscarriage. Left silenced it does not become one of the 'norms' that we consider and are mindful of when speaking with others about children and family.

Listening to this voice, I often returned to a statement Sara made: "...from that point onwards my experience of learning about what was happening to me was through other people." Sara knows the value of social knowledge, understanding that people learn from

each other, and through relationships. Yet as Sara's story shows, silencing can impede access to trustworthy and much needed, social and collective wisdom.

**The Voice of Wisdom.** This voice spoke with urgency and conviction. I heard Sara speaking from the present with insight, holding wisdom forged through 'seeking' and through experience. "I know because I've miscarried. I know because of what I want.", she said. This voice spoke clearly when Sara talked about a recent occasion where she felt comfortable sharing with her colleagues that she was having a challenging day.

*I told my truth. But so many people can't and I definitely wouldn't have been able to do that in an early pregnancy. That wasn't who I was back then. I'm a mum of two and two miscarriages so I've had grief and feelings, that sort of level of wisdom that comes from time.*

Hearing this voice, I thought about how, unlike the other women I talked with, Sara seldom expressed feelings of guilt, shame or self-blame. I wondered if this was due to her tendency to locate her experiences within that of the collective. She knew miscarriage was common, repeatedly citing statistics, and called out the silencing and isolation that occur at a societal level as propelled by patriarchal forces and broader social norms and conventions related to death, and questioned the ways in which the language we have available to speak about miscarriage could be transformed to resist the norms and conventions that cause harm to, and punish, women who experience miscarriage. In doing so, she refused to take responsibility for something she was not responsible for, resisting the notion of the neoliberal responsible individual that holds women at fault and prompts shame and self-blame.

Hearing The Voice of Wisdom, I heard a pull toward advocacy and inclusion. This voice spoke firmly, drawing a critical lens to how women are treated in our society, and to the way miscarriage is constructed and understood. It urged the importance of acknowledging people who miscarry who do not identify as women, as well as women without partners or

without supportive partners, and women within marginalised cultural or social communities. Sara's wisdom extends outward, a rallying call for a collective shift toward prioritising women's wellbeing.

*Let's not be the ambulance at the bottom of the cliff, kind of thing. Let's understand that supporting people in these early gestation times is better for everyone, obviously. ... So, bring it all back and support the mother. Put the mother at the middle of the conversation. Put the mother first emotionally and then you have an amazing society.*

Calling everyone, including herself, to account (*Let's*), Sara urges us to see and acknowledge women in early pregnancy, whether their babies live inside them or have died, as mothers. We can recognise women who miscarry as mothers and as human beings who are going through something meaningful—the death of their baby. By acknowledging grief in miscarriage, and by breaking the silence, we can draw grief and miscarriage into our collective space, honouring women as integral to the wellbeing of our society, and worthy of care and support.

## **Claire's Story**

### ***The Plot***

When Claire and her partner found out she was unexpectedly pregnant, they were thrilled and happily shared the news with others. Claire was crushed when not long afterwards, she miscarried. Her experience of sudden heavy bleeding, dizziness, and painful cramps mimicked an unusual experience from years earlier, leading her to wonder if she had been pregnant, and miscarried, before.

Struggling to cope with her sadness, and feeling burdened to care for others when speaking of her pain socially, Claire no longer felt safe in social environments. Particularly at her art school, she began to withdraw from other people and to avoid social situations. She found creating art to be a helpful way to express and work through her pain. She was upset,

however, to have her art belittled and made light of when she shared it with others and explained how it expressed the grief and pain she felt.

Sadly, genetic testing revealed an inherited genetic condition that was likely to cause miscarriage. Claire became pregnant again, and again her baby died early in pregnancy. This time, the physical miscarriage was slow to resolve. Given medication to aid the process multiple times, Claire experienced months of bleeding and passing clots before ending up in hospital. Worried the recommended surgical procedure might scar her uterus, compromising her fertility, Claire requested a less invasive approach. She was treated with disdain by healthcare providers, and underwent painful procedures with no offer of pain relief.

Claire and her partner pursued IVF, and following one unsuccessful round, Claire became pregnant using donor sperm. She was ‘on tenterhooks’ the entire pregnancy, however nine months gave birth to a living daughter, and she quickly settled into, and enjoyed, motherhood. She was hopeful that one of her three remaining embryos would lead to a living sibling for her daughter, but sadly, Claire experienced two transfers that did not result in pregnancy, and another miscarriage. She was hit by a fresh wave of grief as she came to terms with not being able to have another living child.

Claire and her partner separated, and today they share the care of their daughter. While she feels like her experiences of miscarriage are in the past, she also feels like they have become part of who she is and have changed her identity in meaningful ways.

### ***I Poems***

Claire’s I Poems frequently expressed what she *felt* and what she *feels*, giving a sense of her journey as one that was embodied, emotional and deeply connected to and guided by her feelings. I heard this strongly in the follow I poem, expressing Claire’s navigation of social relationships at art school.

### **Pulled My Shutters Right Down**

I felt like I should be coping

I felt

I'd come from

I'd been

I was always

I felt like this whole experience had pulled my shutters right down

I feel like

I've still got them there

Claire felt an expectation to 'cope', aware that social norms of miscarriage being an unspeakable and insignificant event (Bute et al., 2019; Frost & Condon, 1996) produce expectations for women that they should hold their feelings alone and move through the experience quickly (if indeed, there is believed by others to be any grief or loss to cope with). She felt that talking, grieving openly or 'not coping' would not be tolerated, or would be considered socially unacceptable, causing her to feel unsafe in social situations and to 'pull her shutters down' and withdraw into herself as a protective strategy. Her I poem details how miscarriage compelled a movement away from who she was, and how she had related to others (*I'd come from, I'd always been, I always was*), which in the context of Claire's story, was openness, and feeling ease in her connections with others, to a new place of distrust and disconnection. The 'shutters' are still down for Claire, signalling an enduring shift in how she relates to others and the world around her that continues to this day. Claire's experiences of the lack of support for her grief and pain after miscarriage, and the threat to emotional and

psychological safety and wellbeing this produced for her, has meaningfully changed the way that she walks through her social world.

Listening to Claire's I poems I heard how guilt in many forms was a source of conflict for Claire, particularly arising through relationships with family. In the first stanza of the following I poem, Claire recounts the guilt she felt as she withdrew from her sister. In the second stanza, she expresses guilt related a family member's new baby.

### **Guilt**

I had so much guilt

I just wanted to shut down and not speak

I just couldn't

I found it was the feelings, the guilt about it, that was the real kicker

I had more guilt

I couldn't even look

I've met her now

I don't know if she'll ever know

Claire's urge to 'shut down', to 'not speak', and to withdraw from her family because it was painful, sat alongside her immense love and care for her family, creating internalised conflict that caused intense feelings of guilt and pain. To protect herself from her own guilt and feelings, she disconnects and withdraws, unable to 'look' because it is too painful. She shields herself, holding her feelings alone in a place that feels safe, enclosed from outside threat.

Pain and guilt were also evident in the following I poem, where Claire remembers seeing her partner hold a family member's baby.

### **I Couldn't Provide That**

I was just a mess

I didn't realise

I was just

I remember his mum putting this baby in his arms

I was just like *you don't have that with me*

I just couldn't see

I couldn't provide that

While Claire wanted to share in celebrating her family's joy, witnessing her partner holding a baby was so confronting that Claire felt unable to look, feeling torn between honouring her own feelings of pain, and honouring her feelings and connections with others – a conflict so heavy and painful that she had to turn away because she had learned, through previous negative social experiences and the responsibility she felt to prioritise and care for the emotions of others, that she was unable to speak of this pain to socially.

I heard another form of painful guilt in the I poem's final line: *I couldn't provide that*. Being unable to fulfil the social expectation of having a child (Russo, 1976), Claire feels the pain of not living up to the norms and expectations of womanhood. Feeling it was *her* responsibility to 'provide' a child, she feels guilt, shame, and self-blame. Claire's I poem

speaks to the emotional distress that can become overwhelming when women internalise these social norms and expectations, yet are unable to meet them.

### *Contrapuntal Voices*

**The Voice of the Duelling Dogs.** This voice was pained and sorrowful as it spoke to Claire's experiences of internal and relational conflict. Naming this voice, I borrowed a metaphor Claire used as we discussed the confronting pain of seeing loved ones who were pregnant, or had babies. "'Cause you gotta be happy for them, as well! ... you've got that real duelling emotion thing going on. Like two dog's fighting, isn't it?", she said. One 'dog' is Claire's grief so overwhelming it becomes unbearable to even look at a pregnant person or baby; the other 'dog' is the love and joy Claire felt for her loved ones and their babies. It is difficult, socially, to hold both joy and grief, as Claire knows, because feeling her pain in relational space had made her feel responsible for other people's responses and emotions. As such, she withdraws, but then feels guilty for not showing her love and care for her loved ones when they were pregnant, or had babies.

Claire extended the metaphor to express her need to withdraw: "You just want to lick your wounds, don't you? Take yourself off somewhere quiet and deal with it". The metaphor emerged again as Claire recounted her grief of not having another child.

*That was another grief, of not being able to have that second kid. 'Cause again those duelling dogs... you know, I'm really grateful for this kid I've got, and she's everything, and I don't ever want her to feel like she's not enough. But I kind of saw someone next to her.*

Beyond the pain and grief of losing her baby, Claire experienced pain borne from feeling as though she *should* be happy to have one living child, or that another woman was pregnant, or that a loved one had a baby, when at the same time she was also experiencing grief and distress. Claire had few options but to tend to her 'wounds' alone, as to respond to

another woman's pregnancy or to a new baby with the presence of pain or grief would be to allow her pain to infringe on a 'happy' moment in a way that would be considered socially unacceptable. Furthermore, her pain and grief was so insurmountable that she was unable to tolerate the feeling of becoming responsible for other people's discomfort about her situation. With it all being too painful, too much, Claire retreats on her own to 'lick her wounds', and spaces for connection and relational care were closed down. Claire was left to hold her pain alone, and to feel the added pain of *having to* hold her pain alone.

**The Guarded Voice.** A pivotal moment I returned to often was Claire's early experience of disclosing her miscarriage to people at art school. She felt pitied, or that she had upset them and needed to pretend to be alright for their sake, experiencing her own grief while also taking responsibility for the burden of caring for others. Feeling unsafe to express her grief, Claire's 'shutters came down' as she became guarded.

The Guarded Voice was vulnerable, distrustful and self-protective. I heard it speak to Claire's experiences of navigating social media after miscarriage. "It's kind of a blessing and a curse, isn't it? You really have to prime your feed. Block lots of people. Self-protecting." It spoke to Claire's need to feel safe, a concept reinforced by a counsellor Claire spoke to: "One of the things that a counsellor reflected back to me was finding your safe spaces, and [my art school] was not a safe space". Claire's need for 'safe spaces' reflected her need for safe *people*, and safe social spaces.

*I felt like I was constantly judging people to be a safe space, or not. And also 'cause I was sort of early 30s, there was a lot of people—every time we met up there'd be another pregnancy announcement. So I was probably protecting myself.*

For Claire, how others responded to her miscarriage, and how this in turn increased her pain and distress, made the world seem unsafe. Holding her pain and grief alone, she was confronted with that pain and grief each time she heard a pregnancy announcement or saw a

loved one cradling a new baby. She held this newfound sensitivity as she navigated social interactions, cautiously, becoming guarded to keep herself safe and to prevent the pain from becoming overwhelming and ‘too much’.

Moving through Claire’s story *The Guarded Voice* became emphatic and brazen. I heard distrust, suspicion and anger sitting alongside vulnerability, particularly as Claire recounted her experiences within the healthcare system.

*I remember one doctor coming in when I was in that third [miscarriage] and they were just like, “So how many children have you had?”, and I was like, do you mean this one bleeding out of me right now? Read my fucking notes, I haven’t had any children.*

Claire was furious that she had to inform the doctor that she had no living children when he should have read her notes and entered their encounter informed and sensitive to her situation. That this doctor had not bothered to read Claire’s notes was a dismissal and disregard for all that she had been through, and how that was brought to bear on the current moment she was going through. This was one of many instances of insensitive and uncaring ‘care’ Claire received in healthcare settings. Another doctor, two hours late for their appointment, offered no apology and bombarded Claire with medical jargon. When Claire stated she had questions, he looked pointedly at his watch. For women experiencing miscarriage, the authority and the needs and wants of the medical institution, and of medical professionals, is privileged over their own needs and wants.

*The Guarded Voice* also spoke to Claire’s distrust and concern about how women’s bodies are treated in medical settings.

*I was very anti having a D&C, because from what I understand it’s a blind procedure, and I don’t think you’d do that on any bloke, would you? You wouldn’t be going up there scraping things out on any bloke’s organs.*

Claire explicitly points to the inadequate and harmful care she received as gendered and sexist, believing her body would not be treated in such a way if she were a man. As such, she declined the invasive procedure and instead requested a drug to aid her body to complete the physical miscarriage process.

*...they basically had me on the bed, pulling this out of me... it was just like, no pain relief. Nil by mouth. ... I felt like they were punishing me, in a way. For not going through the D&C, but maybe that's just how I internalised it. There was no pain relief. It was just like, speculum in. And I remember them just leaving and leaving me with the speculum in, as well. ... It was pretty grim. It was really traumatic.*

Claire became guarded in the medical context, protecting herself by calling out insensitive comments, advocating for herself and refusing a procedure that might harm her. However, she felt her unwillingness to be a gentle, compliant woman patient led to her being treated even more harshly, rather than as a mother in physical and emotional pain after losing her baby, in need of emotional care alongside physical care. With no space to feel, and be, vulnerable with others, her 'guardedness' was the only way she could keep herself safe.

Bringing Claire's story to present, I had a sense that the 'duelling dogs' have quietened, and while guardedness lingers, there is more ease. Claire expressed that she had 'moved through' her experiences, which have settled in as 'part of her'. I heard this in the other women's accounts. Rather than a point of 'resolution', miscarriage continues to move through the women in diverse and embodied ways, part of who they are and how they move through the world around them.

## **Katie's Story**

### ***The Plot***

Struggling to get pregnant, Katie and her husband pursued fertility treatment. Following an investigative procedure, Katie was delighted to find herself unexpectedly

pregnant. However, at an early scan she was devastated to learn that her baby had no heartbeat. Katie miscarried at home, and was visited by her sisters and her mum, who were kind and understood how much the baby had meant to Katie. Responses from some friends, however, made Katie realise how ‘taboo’ miscarriage was, and she felt like people ‘didn’t know what to do with her grief’, electing to stay silent, or offer meaningless and sometimes harmful platitudes, such as “at least you can get pregnant” and “maybe there was something wrong with it”.

Katie and her husband continued fertility treatment, and following an intrauterine insemination procedure (IUI) Katie became pregnant. Once again, during an early scan, Katie found out that her baby had died. She opted to miscarry at home, supported by her husband, however this time Katie experienced extreme pain and heavy bleeding that was terrifying and distressing for her.

Katie became disheartened. At a wedding she experienced a ‘real watershed moment’ as her and her husband were asked repeatedly, by other guests, when they would try for a baby. Upset, Katie told her husband she wanted to give up. After a heartfelt conversation, however, they decided to continue trying.

Following another IUI, and another pregnancy, Katie finally had a living baby in her arms. She was happy, and loved motherhood, and a year later resumed fertility treatment, hopeful for another baby. She became pregnant again, yet sadly, experienced a third miscarriage. Katie felt she could not take any more pain and disappointment, so she stopped trying for another baby. A year later, still hopeful for a living sibling for her daughter, she decided to give it one last shot. While trying to pinpoint a time to undergo IUI, Katie and her husband were surprised to find out Katie was already pregnant. Nine months later, Katie’s second living baby was born.

Katie's story is one of mustering enormous strength and resilience to navigate gruelling fertility treatment and clinical systems to become a mother to two living children, while also holding the grief of losing three precious babies along the way. Her journey was difficult, but ultimately she found herself in a place of gratitude, appreciation and peace. "It's ended and there's something good at the end".

### ***I Poems***

Katie's I Poem drew me to the complexities of agency and choice that wound throughout her story. Notably, a lack of agency was present through her experiences of trying to conceive and fertility treatment. In the following I poem, Katie struggles to feel a sense of agency within the medical system.

#### **I Know I Still Want**

I had to have counselling

I wound up talking to this woman

I don't know

I had to

I was just like, what the fuck?

*I think my situation's a bit different*

*... it was the second baby I've lost*

*I'm stressed*

I was just like, what the hell?

I don't know

Was I supposed to feel better?

I was

I'm like, "*Well,*

*I'm fine,*

*I guess.*

*I know I still want to try and have a baby."*

I do wonder

I don't know

I had to

I was

I didn't have

I don't know

I was in limbo

I had been pregnant

I had had a heartbeat

I heard Katie's frustration (*What the fuck? What the hell?*) and confusion (*I don't know, I do wonder*) as she navigated clinical contexts and care where she *had to, had to, had to*. She voices her frustration about being *required* to speak to a counsellor without being informed "what her credentials were or why I had to speak to her". Whilst this is an example of the system responding to emotional wellbeing, it is still the system assuming, and forcing upon women, what they think is necessary and needed, without listening to and genuinely hearing a woman tell them what is wanted and needed. For Katie, the expectation to attend counselling was a continuation of her experience as a docile patient enduring relentless

clinical investigation and intervention of her physical body. Furthermore, she rejected the expectation that she should ‘feel better’ when her babies had died.

Responding to the loss of agency and control over her journey to motherhood, where she had to enter the clinical context of fertility treatment, and where despite her longing her babies died, I heard Katie steeling herself, connecting to what was important to her (*I know I still want to try and have a baby*). In the last stanza she affirms what she knows is real, feeling her own embodied wisdom: *I had been pregnant, I had had a heartbeat*.

Katie’s I poems also spoke to feeling ‘done’ in moments where enduring infertility, clinical treatment, and the pain and grief of multiple miscarriages, had become too much to bear.

### **I’m done!**

I just remember that being like a real watershed moment

*I don’t want to talk about this*

*I’m done!*

*I don’t want to go through this anymore*

*I don’t want to talk to anyone*

*I just feel like no one gets it*

### **I actually just can’t**

I’m done

I don’t want any more babies

I can’t have another miscarriage

I actually just can’t

These I poems convey Katie's exhaustion and overwhelm, as she feels *unable* to keep going, as though she 'actually just can't'. While she feels an inability to continue to endure the relentlessness of her situation and the lack of understanding and support from those around her, I also hear Katie acknowledging and asserting her boundaries regarding what she can tolerate, and what she cannot tolerate any longer, as she takes back some control of her body and her experiences. Placing these moments of feeling 'done' in the context of Katie's story is critical, too, as these moments were followed by Katie *choosing* to continue through reconnection with her longing for a baby.

As Katie's I Poem unfolded, it moved into hopefulness, optimism, and expressions of joy and clarity as Katie became a mother to two longed-for living children.

### **Sun through the trees**

I do have these real moments of peace

I choose to finish work early

I just have these feelings

*This is what I'm meant to be*

I just know, the sun through the trees

I am really present and aware

I'm really grateful

I don't resent my children

I don't think I need to be away from them

I wouldn't

I actually really like my kids

I've been through so much to get here

This I poem conveys Katie's arrival in the present (*This is what I'm meant to be, I've been through so much to get here*). Here, she has agency (*I choose*) and is able to live in, and appreciate, her present experience. This is poignant, because for much of Katie's journey she battled uncertainty, unsure if she would ever live her hoped for and imagined future. While her journey was arduous, ultimately she was lucky to hold two babies in her arms, and she has found peace, gratitude, and fulfilment through mothering living children.

### ***Contrapuntal Voices***

**The Voice of Fortitude.** This voice was strong and had momentum, propelling the movement of Katie's story through detailed accounts of what she had to endure, and how she was able to endure it. I named this voice from Katie's account of her response to the counsellor who suggested considering life without a baby.

*I know I still want to try and have a baby. I've been reassured that my problems—while they don't know exactly why we can't have a baby, they're pretty confident we will one day. So it's just fortitude about keeping going.*

The Voice of Fortitude recounted the strangeness of the clinical context of fertility treatment, using phrases such as *super weird, super strange, so odd, tedious, cold* and *pointless*, as well as negative terms to convey Katie's experiences within clinical spaces, including *horrible, horrific, really crappy, and incredibly painful*, to depict what Katie had to endure on her path to motherhood: a tough journey of painful procedures, despair as her babies died, and uncertainty about her future. It spoke to Katie's experience of undergoing an IUI.

*It's a pretty tedious process. ... All the meds, all the stimulation... this stuff goes on for weeks. People have no idea. You can get a really long protocol and it still might not even work out. There's blood tests every day, there's scans and all that palaver.*

Hearing The Voice of Fortitude, I began to understand the potency of Katie's longing for a baby. Her journey was *tough*, and as such, the strength she needed to endure such physical and emotional pain was formidable, bound in her strong desire to become a mother. This voice also spoke to journeying through pregnancy after loss. Katie struggled with anxiety and nausea but felt unable to voice her difficulties.

*That was really hard too, because societal expectations, social support was like, you must be so excited! And I felt like I wasn't allowed to complain about it. I felt like I couldn't put into words some of the anxiety and the fear. And actually I wasn't that excited. I was going to be excited when I saw my healthy baby. Beyond that it was just like, it was just endurance.*

The expectation that pregnant women be joyous and grateful led to emotional tension for Katie, as instead of excitement she felt anxiety and fear. Not living up to social expectations of pregnancy and motherhood caused Katie distress, and inhibited space for social support. Much like Claire, being unable to voice those aspects of experience that go against the norm, or voicing them and being responded to with dismissal and lack of understanding, left Katie alone in those experiences and feelings.

**The Ever Hopeful Voice.** This voice was clear, articulate and conveyed optimism. There was minimal overlap with The Voice of Fortitude, suggesting Katie's need for fortitude to endure and survive painful medical procedures and cold clinical environments, and to wade through her grief, suppressed her to ability to feel hopeful about the future. The voices did speak together, however, during Katie's 'real watershed moments': those times where Katie felt defeated yet decided to keep going, keep enduring, ever hopeful for a baby.

Mostly, The Ever Hopeful Voice spoke further along in Katie's story. It told of the possibility for transformation, urged that we can better respond to, and support, women during and after miscarriage. "I hope there's change", this voice said. "I remain ever hopeful that we have harder conversations all the time. We talk about things on social media and online and on LinkedIn now that we would never have discussed years ago." Katie is buoyed by seeing glimmers of a shift in how society understands miscarriage, as the death of a baby, loved and grieved by its mother, such as sympathy cards specifically for miscarriage, created by a local poet. Katie's Ever Hopeful Voice made a rallying call for miscarriage to be understood differently, to see it as *meaningful* and to treat it with as much care as we would other traumas that a person might experience. Katie outlined her hope for how workplaces might respond to miscarriage.

*There should just be genuinely good HR processes. It would be no different if you have a family member diagnosed with terminal illness, [and] you had to manage it. You had a catastrophic car injury. You would work out a scheduled return to work with check-in's along the way. You would actually do that.*

The Ever Hopeful Voice urges us to treat miscarriage with the same compassionate care provided in other situations, such as following a car accident, or the bereavement of a loved one (which miscarriage *is*, it is just seldom recognised as the bereavement of a loved one). By shifting our understandings of miscarriage, we can open pathways to better know how to best support and care for women, and meet their needs, when their baby dies during pregnancy.

The Ever Hopeful Voice believes we are capable of breaking the silence of miscarriage. "I think even though people piss us off or may not say the right thing, they probably genuinely don't intend to do that, they just don't know what to do", expressing hope that people can, and will, care and that it is possible for them to 'do better' once they learn

what to do. Hearing this, I hear Katie's compassion for others, including those whose responses and actions hurt her. Extending compassion, she asks for compassion in return: an end to the silence and a movement toward transforming how we know miscarriage so that we may better care for each other.

## **Louise's Story**

### ***The Plot***

Louise and her husband were delighted when she first became pregnant. Excited to share the news with her parents, Louise was devastated when "...they just flipped out. They were yelling, they were swearing, they were telling us we ruined our lives...". Angry, she broke off contact with them. At 10 weeks along, Louise noticed she was bleeding. Sadly, a scan showed that her baby had died. While she wanted to hide away and 'not face the world', she felt well supported by friends, who sent flowers, organised a meal train, and sometimes visited to talk and share their own stories of miscarriage. A close friend took a day off work to drive Louise to the hospital for her D&C, and gifted her a necklace to acknowledge her loss. Likewise, Louise's mother-in-law gave her a pearl necklace, telling her 'pearls are for grief'. Louise's manager at her job in early childhood was less supportive, denying her request for time off.

Louise became pregnant three more times, each time suffering a devastating blow when her baby died early in pregnancy. With every loss her pain, grief and suffering grew, and her feelings began to overwhelm her. Struggling to cope, she began feeling like she no longer wanted to live. Recognising that she was in heavy distress, she elicited support from a colleague, and told her husband and close friends how she had been feeling. They wrapped around her, supporting her to access counselling, which helped to ease some of Louise's distress.

Desperate for understanding and care, and more space to talk about what she was going through, Louise started attending baby loss support meetings. At times she found listening to other people's stories hard, because it hurt to hold their grief alongside her own, but she persevered, finding comfort through connection with others who had similar experiences.

Still hopeful for a baby, Louise and her husband pursued fertility treatment. They undertook one round of IVF, which involved three embryo transfers, but sadly, none of them led to a living baby in Louise's arms. By this point, Louise had lost seven loved and hoped for babies. The demands of fertility treatment and the heaviness of holding so much grief had taken a toll on her relationship with her husband, and they divorced.

Today, Louise has come to terms with being a mother with no living children. All seven of her children are honoured and cherished by her. She continues to find comfort and connection through baby loss support communities, and is now in a position where she supports others. She finds particular solace within a support group for parents with no living children, who she understands are 'quite a minority' within the wider baby loss community. With them, she feels most seen and understood.

### ***I Poems***

The following I poem expresses Louise's response to her parents' hurtful reaction to her first pregnancy, followed by her informing them that she had miscarried.

#### **Heartbroken**

I didn't ring them

I didn't speak to them

I didn't text them

I didn't email them

I rang them and said,

*"You got your wish. Your grandson's now dead".*

I was just like, wow

I was heartbroken

Louise's heartbreak is moving, encompassing disappointment in her parent's reaction to her pregnancy and their consequent absence when she miscarried. She temporarily severed all contact with them. Eventually, she evocatively confronts them: "You got your wish. Your grandson's now dead". By using the word "grandson" *she* defines their relationship with her baby and affirms her status as a mother. Asserting these relational ties brings the reality of Louise's experience and heartbreak to the fore, confronting her parents with the reality that is so often denied and silenced that women who miscarry are mothers, too, and that a baby—her parents' grandson—has died.

Louise's I poems often expressed her *wants* and her *needs*. Her *wants* often related to what she *did not want* in social relationships (*I didn't want to make him feel he had to come home, I didn't want to freak them out, I did not want to do this in front of the kids*). I noticed a reluctance to burden others, with Louise treading lightly to mitigate distress for other people, taking on the responsibility for their responses to her grief and pain, much like the other women I spoke with. Louise's expression of her *needs*, on the other hand, were varied. At various times she needed space, time off, and time out, while other times she needed connection and someone to reach out to, speaking to the way people who are grieving and

navigating trauma need different things, at different times. The following I poem holds the interplay of elements I heard through Louise's expression of her wants and needs.

### **I Needed That Connection**

I found the meetings really confronting

I didn't really enjoy going

I wanted to go at the same time

I needed that connection

I never told anyone about [my first two babies<sup>4</sup> who died]

I only ever talked about [my third and fourth babies who died]

I didn't want to be pitied

*I'm really not a failure,*

*I promise.*

*I feel like one*

*I'm really not one*

Louise expresses internal conflict and tension. She did not enjoy support meetings, finding them confronting, yet she also wanted and needed the connection that she found there. Given Louise so openly spoke of and cherished all seven of her children in her conversations with me, I was surprised to hear that having lost four children, she chose to

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<sup>4</sup> Like many of the women, Louise shared the names of her babies with me. In telling her story, she often used their names, as well as terms like 'my children' and 'my eldest'. Her children's names are extremely important to her, and it is important to her that they are spoken and heard, and it important to me to recognise that here. However in order to maintain confidentiality and anonymity I have needed to remove their names.

only speak about two of them in the support group. Even within a supportive space of shared experience and connection, she felt the need to temper her story, as if four miscarriages were *too many*, and would induce pity from others. Contrasting this with how Louise talked with me in the present, such as using their names and honouring their birthdays each year, highlights how breaking the silence, finding meaningful connection, and relieving herself of the responsibility of distressing others, has moved Louise to a place where she can openly legitimise their existence of all seven of her children, and herself as a mother, with more ease.

### *Contrapuntal Voices*

**The Voice of Connection.** This voice was calm and contemplative, speaking to nurturant care and bondedness. It used positive descriptive terms often, such as *nice memory, awesome, amazing friend, really special, really cool, perfect, amazing support* and *total love*. To name the voice, I returned to something Louise said that stayed with me: “I needed that connection to people who got it”.

I heard liveliness, fondness and gentle laughter as Louise relived experiences of social connection, such as sharing the news of a pregnancy.

*...my in-laws were pretty much like dancing around the room. And I was like – ‘cause they’d already been through this once, with their other daughter. And yeah and it was like they were hearing the news for the first time ever. They were so thrilled.*

This voice spoke to how powerful connection can be, enabling and providing the conditions for joy as journeys are shared and celebrated together. Connection can also ease the journey of grief by providing a way for pain to be held together. Sometimes, Louise’s experiences of connection were physical and embodied, providing closeness and comfort, such as when Louise’s colleague would check in on her by touching her on the shoulder, or patting her on the hand, or when Louise’s mother-in-law heard that she had miscarried and ‘wrapped her in a huge hug’. Through touch and physical presence, silence can be broken

without words, and comfort provided simply by being willing to ‘be there’ for others without trying to diminish the significance of mothers’ grief through offers of ‘silver linings’ or attempts to ‘fix’ their pain.

At times, the Voice of Connection spoke to connection that was emotionally painful and difficult to tolerate, like in support group meetings.

*Sitting and listening to everyone else’s stories. And everyone’s got such different stories. And so they were really confronting and everyone’s really highly emotional in those meetings. So I didn’t really enjoy going to the meetings. But I wanted to go at the same time, because I needed that connection to people who got it.*

While connection could be painful, it was important. Being around other people who ‘got it’ eased Louise’s sense of isolation, and provided space for her grief to be acknowledged. Thus, while bearing witness to other people’s pain could increase the salience of Louise’s own pain and grief, genuine and empathic connection enabled Louise, and her experiences, to feel real and meaningful.

**The Denied Voice.** This voice was quieter, subdued and spoke less frequently, but had big stories to tell. Often, it spoke through contrasting experiences of connection with experiences of disconnection. I first heard this voice as Louise told me about requesting time off work.

*I rang my boss on the Sunday and was like, “Look, I’d really like Monday off work because I’m having – I think I’m having a miscarriage. I need a scan to confirm this.” And she was like, “No, you have to come to work. Someone else has called in sick.”*

Louise’s needs were dismissed as not important or deserving of care and compassion, and there was a complete lack of recognition that her baby was dying, or had died. Later in her story, when she lost another baby, The Denied Voice spoke again of miscarriage and her workplace.

*When [my daughter] died I was at work actually. ... I actually miscarried, like, at work. Like full on, bleeding down the legs, sort of stuff. And the situation was I couldn't go home until after the lunch break had finished, for ratio reasons. So I think I had to wait maybe an hour before I was allowed to go home. And I remember sitting on a towel doing mat time with the kids going, I really hope nothing else happens, because I did not want to do this in front of the kids.*

Louise's stark language, "When [my daughter L] died I was at work", drew me sharply into her reality, highlighting that what was central for her in that moment was the death of her child. We cannot help but face the significance of what she was experiencing when we hear such wording. I understood the gravity of her needs and the brutality of her reality—a mother whose child had just died, being disregarded by her employer and being forced to remain at work, and yet Louise still maintained her commitment to connection through her care for the children she was teaching: despite the lack of care shown towards her, she was cared for the children and 'did not want to do this in front of the kids'.

**The Voice of Recognition.** This voice was steady and assured. It spoke about what it meant for Louise to be seen and heard, and to speak and live as a mother, in ways that felt authentic and sincere. Often, this voice recounted experiences of validation within the baby loss community. One of Louise's miscarriages occurred while she attended a baby loss event in a city away from home, and she was met with an outpouring of support and "total love shown by strangers", a whole community wrapping her with love and understanding. This moment was turning point, moving her to entrench herself within the community, accepting their nurturing care and aspiring to one day support others. Presently, an important source of recognition for Louise is a support group for parents with no living children because, through her experiences, she has recognised that there is a difference between bereaved parents with

living children, and those without; a difference that must be acknowledged and attended to.

Louise described the group as “a lifeline”.

*They know what it's like to not have children. To come home to an empty house, or to be triggered by something that people who've since gone on to have children would no longer get triggered by. Like, seeing a mother and a child, for example. Can be really triggering when you've just had a loss. But that stays a trigger when you don't have any living children. And so they get that stuff. So we have all this common language, and we have all this connection.*

Louise knows how hard it can be to be recognised, and to recognise yourself, as a mother if you have no living children. This group provides a vital source of recognition for Louise, providing space where she can be seen and validated for who she is and what is going through: a mother grieving her seven children.

Critically, The Voice of Recognition also spoke to recognition from people without personal experience of baby loss. This voice spoke to Louise's experience of a friend's pregnancy announcement during a group dinner.

*She was like, “Oh my god, I'm really nervous to tell you this.” ... I'm like, just tell me your news. And she's like, “I'm pregnant.” I'm like, “Oh. Congratulations!” And I burst into tears. I'm like, “I'm sorry, I'm not actually sad. I'm happy.” But you know it's that happy-sad moment that you're holding. And she got it.*

This voice speaks to the possibility of recognition despite diversity in experience. Together, Louise and her friend recognised and sat with the “happy-sad”. Rather than holding her conflicting emotions alone, or keeping them hidden, there was social space where the messiness and complexity of Louise's experience could be expressed, heard, and accepted.

The Voice of Recognition spoke to numerous times where Louise's motherhood, babies and grief were honoured by others through the provision of physical items to

memorialise and symbolise the children she had lost, such as the gifts of jewellery from her mother-in-law and her friend. These items offered material recognition of Louise's grief, and of her children as real, present and enduring. In this context, recognition means more than simply connection to Louise, it is about Louise being seen and heard as she wants and needs to be seen and heard—as a mother of seven loved children who are central to who she is and how she moves through the world. Louise gravitates towards spaces and relationships that provide this recognition that counters the denial experienced earlier in her journey. From this place she can live authentically, true to her reality as a mother who grieves.

## Chapter Four: A Chorus

In this chapter the women's voices join in conversation, speaking together—something that all of the women expressed was vital and meaningful—honouring both shared connections and diversities as they share their wisdom and knowledge. Together they speak to key narratives I heard woven through their stories: *You're a Woman, You have Children*; *No One Talks About It*; *We're Women, We Suffer*; and *Something Good at the End*. At times, my voice joins theirs as I hear them and respond, and together we offer a collective, and expansive, story of miscarriage and social support.

### **You're a Woman, You Have Children**

Mothering is a socially expected role for women (Russo, 1976). Here, the women speak to how the expectation of motherhood informed their experiences of miscarriage.

*Katie: ...there were definitely times throughout the whole journey and losing a baby, you're literally like, is this it? Like, is this my chance to be a parent that's just literally in the toilet? Like, what's going to happen to me? Like, what's the point of my life?*

*Joanna: Weirdly I thought that my relationship would fall over if I couldn't have a kid. And yeah, that he would leave me, which would make sense, because he's [notably] younger than me, and you know...*

*Louise: You're very much brought up that you're a woman, you have children. That is your role in life.*

*Tess: You have to label it for what it is—it's shame. And it comes with the fact that as a couple, as a woman, you haven't been able to deliver on what society has decided should be your life and your calling.*

Louise puts it simply: “You're a woman, you have children”. The women speak together of the social expectation that women will fall in love, become pregnant, and have a

baby, fulfilling their innate desire and need for a child. By following this path, and living the norm of becoming a mother to living children, the identity of 'woman' can be secured (Russo, 1976). Listening to the women, we hear infertility and miscarriage as a threat to motherhood and womanhood. Katie is fearful, questioning what might happen to her, what her purpose and social role would be, if not a mother. Her understanding of her own self and future was so firmly bound with motherhood that she wondered the point of her life without children of her own.

Being unable to live the norm of motherhood can not only impact a woman's sense of self, but how she is seen, and feels she is seen, by others. The women understood their social worth as tied to their ability to have children. Joanna feared her husband might leave should she not fulfil her 'role of providing a child, believing her relationship to be dependent on her fertile ability. Tess reinforces the notion of women's worth being tied to their fertile ability, speaking to neoliberal assumptions that women are responsible for the 'failure' of their bodies to produce children, noting that being unable to "deliver on what society should be your life' produces feelings of shame for women.

While the women keenly felt the presence and impact of expectations of womanhood and motherhood, they were critical, even exacerbated by them. Together they resisted the norms through signalling how harmful they can be for women experiencing fertility and baby loss. No longer serving them, the norms had become detrimental, undermining their sense of worth and purpose, threatening their identities and compromising their relationships.

### ***What is a Mother, eh?***

Miscarriage calls into question normative understandings of motherhood. Notably, all of the women who participated in this research experienced miscarriage during their first pregnancy, thus their journeys to becoming a mother was tied to their first baby who died. Together the women speak of the ability to claim the motherhood identity after miscarriage.

**Tess:** *One of the points that gets missed by medical practitioners and probably even by society at large is that the moment that you get pregnant you're a mother. Like, in your mind, the baby, like you know it's not there, but you're a mother.*

**Claire:** *I just remember [my brother] coming on Skype, I think it was on Mother's Day. ... He's dangling this baby at me, and I'm just like [gasp]. And I just had to go and hide.*

**Louise:** *My first Mothers' Day rolls around, and I was like, ooh. Like I saw myself as a mother. I thought it would be a day that I was celebrated, and even my ex-husband was like—'cause I brought it up to him—I was like, aren't we doing something special? Is like, today not a special day? And he was like, no, you're not a mother. I was like, ouch! What? ... But even he didn't see me as a mother because I didn't have a living child.*

**Katie:** *Well, what is a mother, eh? ... And that was a thing a friend said to me, that did really resonate, was like, it'll always be your baby.*

When women experience miscarriage, the mother identity can become contested. The women experienced a disconnect between how they self-identify (as a mother) and how they are seen by others (not a mother). This denial of motherhood for women who have miscarried suggests that miscarriage sits outside of the norm of motherhood. Yet, these women *are* mothers, embodying motherhood by giving life to and carrying their babies, and enacting motherhood through caring for, loving, and naming their babies. Despite this, their claims on motherhood are disputed or not easily accepted by others.

Questioning why motherhood is contested for women who miscarry, when they embody and enact 'mothering' and feel that they *are* mothers, we can look at the distinction between them and women who *can* readily and unproblematically claim motherhood. As Louise said, "he didn't see me as a mother because I didn't have a living child". Thus,

miscarriage sits outside of the norm of motherhood, and is instead seen as a failure of motherhood or an event that has compromised motherhood, because of an assumption that a mother has a *living* child. The women, however, challenge this normative assumption through the way they identify (as mothers), through their embodiment and enactment of motherhood, and through their enduring relationships with their babies who died. Listening to the women speak of their motherhood, we can begin to expand our understanding of motherhood to also include those whose babies are no longer living.

*...The Baby Didn't Exist*

The women spoke of how the denial of their motherhood by others frequently sat alongside denial of the existence of their baby. Katie and Tess speak together of the contested existence of their babies, and the liminality of early pregnancy and miscarriage.

*Katie: I didn't have a midwife or an obstetrician because you know, you're not pregnant enough to warrant that service. And they don't really want to hear from you until you're eight or nine weeks and you've had your first dating scan, right?*

*Tess: I think there's this kind of thing that happens around miscarriage that if it happens before 12 weeks, that like, it didn't happen. That the baby didn't exist. And the baby didn't exist and so therefore you don't need help and support.*

Katie felt she was “not pregnant enough” to receive care, suggesting that, contextualised within the medicalisation of women’s bodies and pregnancy, early pregnancy is considered tentative until it can be confirmed by medical technology and the risk of miscarriage has subsided. This speaks to a very firm boundary between miscarriage and motherhood, where a baby only ‘exists’ once the possibility of miscarriage is unlikely. Tess elaborates, suggesting that denial of the existence of the baby means that women are not seen as needing care, because without a baby, nothing of significance has been lost.

In the highly clinical context of healthcare, the failure to recognise the existence of babies not only creates a void of support, but can cause harm and distress for women. Kate and Louise speak together of their experiences of having a D&C.

***Katie:** The one thing about the D&C that was a bit crappy, even though it did end it, was the clinical language. ... They say, “what are we having today”, and they call it “products of conception”. “We’re going to remove the products of conception”.*

***Louise:** I didn’t know that they were going to throw [my son] in the incinerator afterwards, because they talked about this ‘tissue’. Whereas he was my baby, in my head. ... They’re like, “We’re going to, you know, we’ll just dispose of the tissue.” And I was like, “Yeah, I don’t want a tissue. Great.” ... The language they used meant I didn’t know. And when I found out, it was too late to do anything about it.*

Clinical language, such as *products of conception* and *tissue*, worked to deny the existence of the women’s babies, reducing them to biological by-products of failed conception. For Louise, the language used to describe her baby was so discordant with her own reality that she misunderstood what she was being told. Beyond the callous use of clinical language used, the way that Louise and her baby were treated by healthcare providers was careless and brutal. Her baby was disposed of in a medical incinerator without her knowledge or consent, and her ability to engage in grief rituals or processes that may have helped her to process her grief, and honour her baby, and her motherhood, was denied. These accounts speak to a fundamental failure to recognise life and meaning, and the realness of babies that extends beyond biology. Babies lost to miscarriage are real to women and to others who have helped to bring them into being socially and relationally, through pregnancy announcements and expressions of joy, through hope and wonderings of the future.

An important implication of denying a baby’s existence is that women may feel unable to claim or express motherhood, because without a baby how can there be a mother?

Furthermore, denial of a baby compromises the legitimacy of grief, because if there was no baby then what is there to grieve? I did not recognise the wave of emotions that enveloped me after my first miscarriage as grief, because I had never associated miscarriage with grief. Confused, I wondered why I was bereft and struggling, blaming myself for being ‘too sensitive’. Realising, months later, that what I had been feeling was grief, engendered surprise and relief. My experience illustrates how the pervasive denial of the existence of babies, and the lack of recognition of grief in miscarriage, can become internalised by women, inducing distress and shame.

### ***I Have My Babies Here***

While the women’s stories address the expectation of motherhood for women, and the denial of motherhood and of the existence of their babies by others, I also heard the women honouring the ‘realness’ of their babies in diverse ways. The women speak together of making their babies present in the absence of their physical presence:

***Katie:*** *I keep these little glass hearts. ... I’ve got three different ones for each of my miscarriages. One was given to me by a nurse in a fertility clinic, and it had a lovely little poem and she just sort of said, this is just something to hold.*

***Sara:*** *[gestures to tattoo] I have my babies here. These are my two babies who are born. This is me, with my two children. This is also my mother and her children. And then these are the ones I lost. ... After 10 years I’ve found a way to bring them here.*

***Louise:*** *[A friend] bought me this, when [my son] died. It’s a living locket. And she originally put in the infinity symbol, the angel wings, I think she put the heart in. And his birthstone. Oh, his death stone. And then she just kept adding to it, the many times we had another pregnancy. So there’s all of my children’s stones in there.*

Materiality brings the women’s babies and their grief into reality, offering resistance to being unseen, unacknowledged and denied, because the physical representations are

undeniably present and ‘real’ within social and relational spaces. Katie’s glass hearts and Louise’s living locket are cherished gifts, powerful demonstrations of social recognition and responsivity through bringing the women’s babies, their pain, and their love into ‘realness’ within a social relationship. Materiality affirms the existence of the women’s babies, their lives and their deaths, but also their enduring presence in the women’s lives. Furthermore, physical items such as Louise’s necklaces, or Katie’s hearts, can provide ways to embody and enact motherhood, affirming the women as mothers. The symbolism embedded in Katie’s glass hearts embodies her love for her babies, while Louise’s living locket honours her babies lives, deaths and her enduring relationship with them. Sara’s tattoo locates her babies within her wider family network in a way that is permanent and embodied, connected to her through family.

Hearing the women’s stories is an argument for generosity. Namely, relational generosity whereby we listen to and hear women, allowing space to express and define what motherhood means for them, and offer acceptance and validation in return. By enacting and embodying motherhood through and beyond miscarriage, the women trouble our cultural narratives of motherhood where mothers are only women with living children, calling us to question why we gatekeep motherhood, constraining what it can be and who can claim to be a mother. By opening spaces to recognise and connect through diversity we can create movement towards a more inclusive cultural narrative of motherhood that embraces and honours women who miscarry as mothers to children that they love and grieve.

### **No One Talks About It**

This narrative thread, *No One Talks About It*, addresses the silencing of miscarriage. The women speak together of experiences of silencing and how silencing impedes social support.

**Katie:** *[I] didn't realise quite how taboo the whole thing was. Didn't realise that yeah, people didn't quite know what to do with your grief, they didn't quite understand what to say, they thought it was better to say nothing or pretend that nothing had happened. Or the other way. The overly positive, "at least you know you can get pregnant now!". You know, "it's God's way". "Maybe there was something wrong with it".*

**Tess:** *It was just so hard to talk about. And I felt that the times when I was actually brave enough to talk about it, that it just never landed well. So you know, if I pluck up the courage to tell someone about the tremendous heartbreak I'm going through, and I'm grieving for all the things, all the experiences that I never had as the mother of that child... if I talk to someone about that and if they don't respond in the right way, it just makes me shut down.*

**Katie:** *If no one talks about it and it happens to you, and you don't wanna talk about it, how do you know that you're not the only one, right? I mean you know you're not the only one, but yeah, the intensity of feelings are challenging and you think, is it normal to feel like this? Do other people feel this way?*

When Katie and Tess tried to talk about miscarriage "it just never landed well". The 'taboo' nature of miscarriage prevents conversations about miscarriage from occurring, limiting opportunities for those who have not experienced miscarriage themselves to learn what to do, or say, when someone they care about experiences miscarriage. When people do not know what women who miscarry are feeling, need, and want, they may turn to "overly positive" platitudes that, instead of opening space for social connection, can minimise women's experiences, reinforcing silencing through signalling that there is no space to talk of grief, loss and pain. Other people, Katie suggests, believe it better to "pretend that nothing happened", denying the existence of a story and that something of significance occurred.

For Tess, the silence of others taught her to be silent, too. Such pervasive silencing can prompt women to impose silencing on themselves, withdrawing from social connection, and limiting possibilities for social support. Women are left to hold their stories and pain alone, providing the conditions of possibility for self-blame, shame and responsibility for their own pain. As Katie suggests, holding pain alone can lead to wondering, “is it normal to feel like this?”. When spaces to speak of, and to hear, women’s pain and grief are denied, women are unable to connect with others’ stories and legitimate that it is grief that they are experiencing, leaving them wondering whether what they are going through—silently and alone—is abnormal or pathological.

### ***There’s No Norms***

Knowing that one in five pregnancies end in miscarriage (McCarthy et al., 2020), we can question why women feel alone or abnormal in their experiences and grief, opening spaces to critically problematise, challenge and transform the norms that surround pregnancy, motherhood and miscarriage. Talking together, the women often clearly articulated, and resisted, how our social scripts play into and reinforce dominant norms of womanhood and motherhood.

***Claire:*** *When your kid's up to about two, people are asking about the sibling, aren't they? This was like miscarriage grief but reimagined again. So people would be like, "So are you going to give them a sibling?", and there's me still bleeding out my last IVF attempt.*

***Katie:*** *I still have friends that even though they knew—well they probably didn't know the extent—like I've been pregnant five times. I've had three miscarriages, we've got two children. Who still thought, "Oh we always thought you'd be up for another one."*

*Sara: There's no norms. There's no norms to say people miscarry, often. The childless couple might not want to be childless. Stop asking them when they're going to have a baby. Those kind of things. There's no norms.*

*Tess: As a society and a community we need to somehow normalise this thing called miscarriage. You know it's not something that we want everyone to go through clearly, but we need to have a way of supporting people and making it easy for people to talk about in a way that's not going to make them feel socially awkward.*

Sara laments the lack of norms that are responsive to and serve women who experience miscarriage. Instead, societal norms of womanhood and motherhood, whereby women desire to and become loving, good and gentle mothers to at least two living babies (Russo, 1976), are woven through social encounters. These norms feed our social scripts, prompting us to casually ask women when they will try to get pregnant, or have another child. We know these scripts well; they are rehearsed, repeated and uttered with ease, so practiced and socially accepted that they border on flippant. There is a lack of regard or recognition of the pain and anguish these utterances, and norms, can cause for women who are struggling to live the norm or who have no desire to live the norm. Our norms neglect to attend to miscarriage with sensitivity or empathy, or recognise that miscarriage *is* the norm for many woman. Instead, it appears that the norm for miscarriage is a denial and silencing so pervasive that miscarriage fails to permeate our social understandings or discourse. When we are unable to talk about, or listen to, stories of miscarriage, we lack opportunities to transform our norms in ways that enable us to respond with care, dignity and respect to women who miscarry. The norms we do have reinforce and perpetuate the silence of miscarriage, and constrain social support. The norms invite shame and pity that quietens us.

Like the women, I too have felt the sting of being asked if I will try for another baby. At the playground with my son someone unknown to me will say, "Just the one?". I pause

and steel myself, wonder how to respond. My story is not ‘one and done’. My story is of three babies, and of miscarriage. Yet to tell my story veers from that practiced social script, oversteps an unspoken social boundary, and I worry I will cause upset for others. I am learning to get comfortable saying, “I had two more babies that I lost during pregnancy”. I say this because sometimes the other person will say, “I lost a baby, too”, and I feel a space of connection crack open, the isolation eased. I feel hopeful that it is possible to imagine a community where women like me, us, can come together more to share our stories and transform our norms of pregnancy, motherhood, miscarriage and grief.

### ***It was Life-Changing for Me***

The silence that shrouds miscarriage is at odds with the impact the miscarriage can for women. Our social norms, and the medical institutions, tell us that miscarriage is brief and unnoteworthy (Frost & Condon, 1996), a momentary snag on the journey to ‘real’ motherhood, yet for women the experience can be life altering (Watson & Jewell, 2018), distressing (Herbert et al., 2022) and hugely meaningful (Miller, 2015). The women speak together about the impact of miscarriage on their lives and sense of self.

*Tess: I think for women knowing that actually, this is a grief that is going to be with them, it’s going to shape who they are. It’s going to be an identity-shaping moment in their life. Maybe it’ll be a big one, maybe it’ll be a small one, but it is going to have an impact on who you are and how you view the world.*

*Claire: I think people just don’t know how much, how far-reaching it gets into your head. But it can do. Some people just breathe through it and come out the other side. ... But no, I think it was life-changing for me. Completely turned everything around.*

*Joanna: ...now I’m just kind of like, no risks. No risk can be taken here. It’s a quiet life, now. ... The world just needs to stay calm. But it’s weird! Because the person that I was would’ve been doing all kinds of interesting things.*

*Katie: But you do, I 'spose, have compassion and perspective and you do view the world differently and that's probably not a bad thing.*

The women speak to the enduring impact miscarriage had on their sense of self. They allude to permanence, whereby miscarriage can fundamentally permeate “who you are and how you view the world”. The magnitude of this identity shift can be vast and “life-changing” for some, although there is recognition that the impact is diverse across women. Joanna suggests her experience induced a need for self-protection, while Katie speaks of elevated compassion for others. Despite this diversity, the women find connection when speaking of how miscarriage can indelibly impact a woman’s sense of self and how she moves through the world in a way that is significant and enduring.

When our harmful social norms silence and suppress stories of miscarriage, spaces for active engagement and meaningful connection with something of such gravity and significance for women is denied. To not speak of miscarriage is vastly at odds with its magnitude, providing the conditions for social withdrawal as women feel unseen, unheard, hurt and responsible for the wellbeing of others if they dare to speak of their grief. Placing this notion of miscarriage as profoundly impactful and life-altering for women in proximity with the undeniable and pervasive silencing of miscarriage shows the extreme inadequacy of support, care and understanding that exists for women who experience miscarriage; support, care and understanding that may be possible if we open spaces to listen for real and to find connection within the diversity of our experiences.

### **We’re Women, We Suffer**

The “We’re Women, We Suffer” narrative I heard woven through the women’s stories speaks to suffering as something that resides within the experience of being a woman. These words—“we’re women, we suffer”—were voiced by Sara. During her miscarriage, grappling with physical pain and emotional anguish, she came to realise her experience as

common to women. While suffering is a universal human experience, regardless of gender, hearing the women speak together suggests that women suffer, and are left to suffer, in ways that are recognisable as unique to womanhood. Sara located her suffering in that moment as a collective experience: “Like people with really bad endo, or you know, terrible periods, you know, it’s like oh! We just deal with this”, suggesting women endure physical trauma and pain because of their reproductive system, and because of a medical system that neglects to care about women’s suffering. Under the medical gaze women’s physical pain is disregarded and overlooked (Hoffmann & Tarzian, 2001; Zhang et al., 2021) and emotional pain denied, and, as such, women’s pain becomes taken for granted or unacknowledged. Together the women speak of suffering through miscarriage.

***Katie:** I was just screaming for [my husband]. ... They did say it’s like a bad period, but oh, it was nothing like that. Nothing like that. Having been through labour now, it was like a labour. I just had this extreme sense of urgency, wanting to push, blood everywhere.*

***Joanna:** It was very painful. Yeah.*

***Sara:** I couldn’t move my body, it was in this intense contraction, so my knees were up, my arms were up, and I was biting on the mattress on the floor. Like I was on the floor and there was a mattress, and I was biting on it because it just hurt so much. Like I really thought I was in a medical emergency. ... And the fact, [my friend] said to me, “You’re talking to me, and you’re breathing, keep breathing.” ... I think she said, like, should I call the ambulance, and I knew at that point, I was like “No! It’s just a miscarriage.” ... Like oh this isn’t, you know, a heart attack, this isn’t going to kill me. This is something that women have done for millennia, so I’m just going to suffer. You know, like? We’re just used to the life of ‘we’re women, we suffer’.*

***Katie:*** *Why would we do this?! Why would we send women home to their safe space and then have this horrific thing happen?!*

The brutality of the women's suffering is striking, undeniably exceeding physical pain and extending to the terror of encountering a process more bloody and painful than anticipated. Following these harrowing embodied experiences of pain and distress, the women were expected to hold their stories and their trauma alone, further compounding their suffering.

To suffer so visibly, with little support and care, positions women's suffering as acceptable, expected and normalised. Sara's account speaks to this, whereby her pain was so intense she feared a medical emergency. Upon realising her pain was 'women's pain' she resigned herself to managing at home, alone. This signals that women *know* that their pain will be treated as normal, acceptable and not warranting of care (Hoffmann & Tarzian, 2001; Zhang et al., 2021). When I called the gynaecology department at the hospital three times in as many hours, sobbing, worried about the intensity of my pain and terrified by the extent of my bleeding during a miscarriage 20 weeks into pregnancy, I was repeatedly told to remain at home. Eventually, my husband rushed me to the hospital where I swiftly received emergency care and delivered my baby. That experience has undermined my sense of safety within the medical institution. I struggle to feel that I will be believed, or my pain treated as real, or that I will receive the care I need—distrust borne from knowing that as women, rather than be protected from suffering, we are expected to endure, and to endure quietly.

### ***Take Your Pills, Off You Go***

The women's stories detail disregard for their emotional suffering within the medical institution. Healthcare largely focuses on the physical body, with emotional health and wellbeing overlooked. The women elaborate:

*Tess: There was no follow-up after care from either my GP, the afterhours [medical centre] or the hospital. It was literally, you know, take your bag, take your pills, off you go, see you later.*

*Sara: There is definitely a need for the emotional support, not just the medicalised.*

*Joanna: That whole thing about miscarriage. And infertility. You know, the odds of postnatal depression are much higher. I suspect the odds of relationship breakup are much higher. So there's all this stuff that flows on through.*

*Sara: We're not creating the emotional wellbeing next to the physical wellbeing. They co-exist.*

The women lament the void of emotional care for miscarriage within the medical institution, where, under the medical gaze, healthcare is limited to the physical body and disregards or denies the need for psychological care (Lupton, 1997). There is an absence of holistic and meaningful support that recognises women as whole human in need of both physical and emotional care. When miscarriage is reduced to an 'event', rather than a trauma that endures, there is little space or possibility for attending to anything beyond the acute, physical state of miscarriage. Women are then left to navigate the road ahead without professional or holistic support.

The lack of care shown for the women's emotional suffering highlights the boundaries of care within the medical system, where 'care' is reduced to biological and physical bodies and body parts. Even so, I struggle to use the word *care* after listening to the women because the care their bodies received was often brutal. Hearing the women speak together about being in the gynaecology department waiting room, the lack of compassionate, holistic and humanistic care in the healthcare setting for women who miscarry is shockingly exposed.

*Joanna: That whole process was awful from a social services perspective, because the way that you go to the hospital and get the D&C or the pill is you go to the*

*maternity area. And you're sat in the waiting room with all these heavily pregnant women. And you're there waiting for your baby to be taken out. ... It was so awful.*

**Sara:** *There are happy, beaming pregnant people, and small children running around. There is life streaming in front of you, when you know that you failed as a mother.*

**Tess:** *Fuck me, I mean what the hell are they thinking? You know you're sitting there thinking, oh my goodness, I've lost my baby, I'm losing my baby. And you're confronted and have to sit next to, in my case, women who have got this bulging belly and they're literally about to pop.*

**Joanna:** *I had to wait for bloody—like more than an hour. So you know, it was a long wait. And you're just sitting there crying the whole time. And nobody knows why you're sitting there crying. I can't believe that they do that. ... Why don't they just have them sit in a different room?!*

**Claire:** *I got to a point where I was like, right, I'm going to be downstairs having a coffee. When your doctor's ready get them to call me on my mobile, and I'll come back up.*

**Tess:** *But the thing is like they've known about this, I wrote to them afterwards and said look, you've got to sort this out. It's like, and how many years later and the same thing is still happening right? It drives me insane.*

**Claire:** *I've fed back to them since.*

Experiencing the death of their baby, the women were directed to the part of the hospital that attends to women's reproductive bodies, thus the 'care' they received chiefly pertained to their physical bodies, in this case, their uterus. Seen for their bodily parts requiring 'treatment', the impetus of care was to ensure the physical miscarriage process resolved. The brutality of having miscarrying women sit in a waiting room surrounded by

pregnant women speaks to the denial within the medical paradigm to see women as whole and feeling human beings. Their holistic experience is callously disregarded.

The women's outrage is palpable throughout their conversation. Together they are incredulous about being placed in that situation where the potential for distress is so glaringly obvious. Clearly, we have an example of medicalised care that escalates and actually *causes* suffering for women. Adding to the women's outrage is the knowledge that the situation persists and that miscarrying women continue to sit in that room, despite their complaints and protests. Claire and Joanna engaged in embodied resistance. In an act of protest and self-protection, Claire removed her body from the space, requesting a call when it was her turn to be seen. In contrast, Joanna stayed in the room and cried, an expressive and embodied form of resistance as she refused to silence her pain and grief, instead making it visible as she embodied her authentic emotional response to a traumatic environment. Both Tess and Claire lodged feedback with the hospital. Ultimately, the lack of response to the women's resistance, whether by voice or by body, reinforces the denial and disregard of their emotional needs within the medical institution. Change has not eventuated, despite their protests. I have sat in that room, too. Cried in that room, too. Years after some of the women sat there, years after their complaints. Women continue to suffer, and that suffering continues to be ignored at best, tolerated, accepted and enacted at worst.

### ***You Wanna Keep it Quiet***

The disregard for women's needs, circumstances and suffering extended into their employment and workspaces, demonstrating how women's suffering is denied, ignored, tolerated and enacted in diverse ways across diverse contexts. The women speak together here about their experiences of miscarriage, suffering and employment.

**Katie:** *My work was really good, I have to say. My manager was so supportive. But if you had someone that wasn't, was like, "another appointment?" ... Because the issue with miscarriage, with fertility—it's not straightforward. It's not always convenient.*

**Sara:** *How safe are people in their work environment anyway, to have that option? Because people might not talk about a pregnancy for fear of losing their job, so therefore they have to keep something like that really hush-hush.*

**Tess:** *You wanna keep it quiet so that your career prospects aren't harmed, because there are still plenty of professions whereby if someone even catches a whiff about the fact that you might possibly be wanting to take time off to have your family, it's all over red rover from a career point of view, in terms of future opportunities.*

**Katie:** *I wonder if it's changing though, aye. I was just thinking... Like even this year I've noticed a few LinkedIn posts. ... they have been from men, talking about loss, maybe on Miscarriage Awareness Week, or whatever, but it's like I think the narrative's changing where people are more likely to be like, I'm a human. I have a job. This is my experience, it's really awful.*

The women speak to how silencing pervaded their experiences of miscarriage in the workplace. Gender inequality in employment is a persistent and pervasive issue, with women, and mothers, frequently experiencing marginalisation in the workplace (Cahusac & Kanji, 2014; Crosby et al., 2004; Harris & Estevez, 2017; Heilman & Okimoto, 2008; Porschitz & Siler, 2017; Verniers & Vala, 2018). Sara and Tess express how motherhood is not necessarily viewed as synonymous with being a desirable employee, forcing women to suppress their intention to pursue motherhood in order to protect their jobs and career opportunities. To worry that parenthood will harm employment or career opportunities is a highly gendered experience. Men do not need to suppress their desire for fatherhood in the work place setting (Correll et al., 2007; Cuddy et al., 2004). For men, announcing a baby on

the way would be more likely result in a congratulatory slap on the back than concern that their productivity or dedication will be compromised, or that they will be able to get or keep a job, or receive a promotion.

Considering the tendency for mothers to not be seen as desirable employees (Cahusac & Kanji, 2014; Porschitz & Siler, 2017), alongside the norm and social expectation that women must become mothers and raise their children well (Russo, 1979), we can begin to untangle the messy complexity and impossible demands that society places on women, that leads not only to silencing, but also the requirement for women to suffer in silence. Marginalised in the workplace by their reproductive and maternal identities (Cahusac & Kanji, 2014; Porschitz & Siler, 2017), women may feel the need to stay silent about both early pregnancy and the loss of a baby. Thus, the silencing of miscarriage is reinforced and perpetuated within and by the workplace, limiting opportunities for women to sit with, and to process, their grief, and creating barriers to social support. During my conversation with Tess she discussed how the need for anonymity to safeguard career prospects may act as a barrier to accessing community support, such as through a baby loss support group. Given Aotearoa New Zealand is a small country, and given the frequency that miscarriage occurs, it is feasible that a woman might encounter someone known to her through employment settings in a support group context, even in our larger cities. As such, the marginalisation of women in the workplace closes down opportunities for miscarriage support *outside* of the workplace, too.

The expectations and demands of the workplace, and the lack of safe spaces to talk about and be supported through loss, can exacerbate suffering for miscarrying women. I think of Joanna returning to work after one day off and miscarrying on that lime green chair. I think of Louise being denied time off because “someone else had called in sick”, and later sitting

on a towel as she cared for preschool children, the needs of the organisation prioritised over her need for compassion and care.

As Katie suggests, there are employers that do not actively marginalise women for pursuing motherhood, and support women through pregnancy, infertility or loss. Yet, hearing Katie say, “My work was really good, I have to say”, I know she understands that a supportive employer is *not* the norm, and that she was *lucky* to receive support. This mirrors my own experience of working for a company who offered generous leave entitlements, hosted celebratory morning teas when employees went on parental leave, and sent a gift when a baby was born. Resigning from my role in the days following my second miscarriage, my manager was supportive and I was paid out my notice period with no requirement to return to work. This was a privileged position to be in, and like Katie, I felt *lucky*. We should not feel lucky to be supported in this way, because compassion and care should be the norm. Katie voices her hope that things are changing, and that miscarriage is increasingly being recognised in the workplace as a painful, human experience. While some spaces may be seeing movement toward normalising miscarriage as an event that deserves responsiveness, care and compassion, listening to the women in conversation signals that marginalisation, silencing and the normalisation of women’s suffering still remain formidable barriers to overcome.

### **Something Good at the End**

I heard narratives of healing within the women’s stories; journeys from the pain and suffering of miscarriage to healing and wellness in diverse forms. Often, narratives of healing spoke to an assumption that a living baby ‘heals’ women of the pain of miscarriage through providing ‘something good at the end’, a narrative that denies how the pain of losing children can remain even if women are able to have living children, and exclude and constrain

understandings of healing and recovery for women who do not go on to have living children after miscarriage.

**Katie:** *[Having my daughter] was very healing. It's just like, perfect birth. Lovely, textbook kind of pregnancy. Really easy baby. Really straightforward. So, I'm so glad I had that experience. And it really did round things out. But it, ya know, it breaks your heart for everybody that doesn't. Or has multiple miscarriages. Or is left in that weird limbo, like... yeah. Probably why it's so easy to talk now. Because it's ended and there's something good at the end.*

**Claire:** *[My daughter] still says to me now, "I really wish I had a brother or sister." And it's not as loaded now, but I'm just like, she knows the full story. I can just say to her, like, we tried. ... And it was never my intention to have you as just one kid, but that's how it is.*

**Louise:** *I often find that – through no fault of their own – a lot of people who, say have a first loss and then a rainbow<sup>5</sup>, forget all the stuff that happens there. Whereas if you've had a baby and then had loss then it's different, because that stuff is still very present. But for people like myself [with no living children] it's never had a chance to go away.*

**Tess:** *...that shift in identity, if it happens, if you don't go on to have children successfully, is even more acute. Well, in my opinion, it feels more acute.*

This conversation explores diversity in experience between women with living children and women without living children. Katie's expresses her experience of healing when her daughter was born. Her perseverance, suffering and hope led to a baby daughter in her arms, making the hard journey worth it. Louise and Tess, however, contest and reject the notion of healing. As mothers with no living children, the pain of miscarriage endures in a

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<sup>5</sup> Here, Louise is referring to a "rainbow baby": a baby born following a miscarriage, stillbirth or infant death

way that is different than for mothers with living children. Claire reminds us that, even if a woman goes on to have living children after miscarriage, the grief of the death of a child can stay with us in different ways and endure, even if it is not as ‘loaded’ anymore, troubling the notion of an ‘end’ to grief and of a ‘healing’ that is complete.

The women’s conversation speaks to a social assumption that a living baby is a pathway to recovery, repair and healing—a narrative I once bought into. After experiencing miscarriage I encountered the notion of a ‘rainbow baby’; a baby born after miscarriage, stillbirth or infant death. A rainbow baby represents hope and healing, the promise of a rainbow after a storm. On social media I saw women cradling their rainbow baby, restored, urging other women to hold on to hope. I longed for a rainbow baby, believing it would bring an end to my pain. I *deserved* a rainbow baby, I thought, after my suffering. I felt acutely that other people wished for a rainbow baby for me, too. I was frequently asked if I was trying to get pregnant again, and I knew others wanted me to be healed, to know I was no longer sad. I felt that a rainbow baby in my belly or my arms would be me easier to be around. As time passed, I decided not to pursue another pregnancy, yet without a baby to heal me I worried I would never be ok.

Research by Smith et al. (2018) troubles the idea of a rainbow baby as healing, however, as the arrival of a baby after a loss can stir an array of emotions for women, including those that are uncomfortable, such as feelings of guilt related to ‘replacing’ the baby that died or ‘moving forward’ with life. As Claire suggests, the birth of a living child may produce new forms of grief, such as feeling the loss of a sibling for a living child. Thus, while the notion of the healing potential of a rainbow baby can lead to women feeling like they can never really gain healing or an ‘end’ to their grief if they do not go on to have living children, women who do have a rainbow baby may be surprised to find the ‘healing’ they expected does not eventuate, or is not ‘complete’.

We lean on narratives of healing because we want to believe that good things will happen to good people. In our neoliberal society we push the notion that working hard, and being a good, responsible person will lead to success (Alcalde, 2013), thus collectively we are averse to the idea that good, deserving, hardworking people can throw everything they have at something and it still does not work out for them. This neoliberal narrative means that women who cannot or do not go on to have living babies are seen as ‘doomed’, as by not living up to normative expectations for women, we do not expect good things to eventuate for them. Furthermore, grief for women like Claire, who continue to grieve even after they have achieved the ‘accomplishment’ of living children, can be denied.

Critically, the stories told by Claire, Tess and Louise resist the binary of healed/unhealed through sharing their stories of working through grief both with and without living children. Miscarriage did not irrevocably break them. Rather, they embrace ambivalence through speaking of how contentment and acceptance is possible, despite, and alongside, the enduring grief of losing children and not having living children, or finding that having living children did not produce the complete healing that is socially expected to occur. Earlier in Claire’s story she recounted that she is “grateful” that she has a living child, yet still sits with “another grief”. Likewise, Tess has previously spoken about being “settled and content” yet she lives with grief and wariness. From Louise’s story, we learn grief continues to move through her, yet from her experiences spaces of connection and care have bloomed. What I hear in these stories, and what I personally know to be true, is that miscarriage continues to move through women in diverse, complex and far-reaching ways, whether they have children or not. This ambivalence, mess and complexity is the reality of miscarriage.

### ***She Just Held Me***

Expecting women to become healed and to ‘get over’ their loss and grief may constrain support for women who are unable to heal according to those expectations, denying

opportunities to sit within the messiness and complexity of grief. However, the women detailed encounters where others chose to stay with them in their pain and grief, allowing them to feel seen and supported for what they were going through, not trying to ‘fix’ them or take away (deny) their pain. The women speak together of this.

**Sara:** *I was on the phone to my friend, who was guiding me through like almost like a meditation, she’s going, “I want you to breathe, I want you to breathe, I want you to lie there, feel this and know that you...” ... So she was miscarrying with me. And I was like, afterwards I said to her, “That must’ve been so hard for you, you had a baby the same age, you were pregnant at the same time, and you were guiding me through a miscarriage.” And she goes, “I just did what had to be done. You were on your own. I was the only one there”.*

**Joanna:** *I remember [my husband] sat with me on the stairs in our house and he said afterwards, “Did I do the right thing?” He felt useless. And I said, “Well you sitting and cuddling me, that was all that was needed.”*

**Katie:** *I’ll always remember a friend who was just like, “I don’t know what to say. I just can’t imagine what you’re going through.” And I was like, that is the best thing to say, because no one can ever imagine someone else. And then she just sat there, and she’s like, do you want a cup of tea?*

**Louise:** *I got really triggered [at a support meeting] ... so I left the room. ... I was sort of just sitting on the floor, just sobbing. ... [My friend] sat in front of me, so I was sort of like sitting out with my knees round me like this, and she came and she put her legs on the outside of mine. ... I remember this pressure, like she was pressing on my knees with her knees. And she was like, sort of like gripping my forearms. ... I don’t know how painful that position must’ve been for her to sit in, but like, she just held me. ... She just sort of gave me a really strong physical presence, touch. Didn’t say anything.*

*Didn't try and make me feel better. ... [Another time, a member of the baby loss community gifted me a stacked stone sculpture], she was like, "I think you should take this home to remember this, and that you can rebuild your life, and that, you know, it doesn't have to be strong, like it can be shaky". It just hit me in such a big way.*

The women speak of how powerful it can be to have someone see them in the 'mess' of their experience and choose to stay with them, in that pain, without trying to 'fix them' or expect them to be 'fixable'. Clearly, the women did not need other people to say anything profound, or to assure them that everything would be ok. Staying on the phone, cuddling, making a cup of tea, just being there—these simple acts provided comfort. Choosing to be in the moment with women can dignify their pain, allowing them space to feel their grief and have their pain acknowledged, enabling empathy, care and support that does not deny what they are going through or place expectations for 'getting over it' that constrain women from sharing and connecting when 'getting over it' is not possible.

Notably, while some women detailed support encounters that related to the acute, physical phase of miscarriage, Louise detailed numerous supportive encounters and connections, often with other members of the baby loss community, in the months and years to follow. Within that community Louise does not have to be healed, peaceful or stable. She can be 'shaky', and rather than being solely responsible for her pain alone, there is space for her pain to be felt, dignified and collectively held.

Crucially, the women's conversation speaks to possibility and potential for connection *through* diversity by demonstrating that responsive and meaningful support can be provided by people without lived experience of miscarriage. Furthermore, support is possible with relationships that carry their own complexities, such as with the pregnant friend, or the friend who feels they do *not* understand. We have heard previously about how the women have suffered when they have been around pregnant women or women with babies, and how

isolating and painful it feels when their grief and suffering is not understood or when people do not know how to respond, and yet in this conversation, we see possibility for support and connection even within such social interactions and relationships.

Knowing that the pain and grief of miscarriage is weighty, and enduring, we must reject the notion that women should, or even can, ‘heal’. Instead, we can accept that women’s experiences will continue to move through them in diverse ways, and we can choose to stay with them as they journey through pain, opening spaces to feel their pain with them, breaking processes of silencing, and easing isolation. We can choose to ensure that mothers, grieving the loss of their loved babies, are given space to grieve, and will not grieve alone.

### ***You Want Empathy from Someone That Knows***

Miscarriage and baby loss communities are an important source of support for many women, however bringing the women into conversation we hear how relying on women with lived experience of baby loss to provide support for women going through miscarriage can place a heavy burden of care onto those women, who are already in pain, distressed and grieving.

*Claire: There is the [local] miscarriage group which was running. I couldn’t go to that after the first one but I think I did after the second. And I’m glad I did ‘cause I met some mums who—there was someone else who was going through the [same genetic condition]. So everything that I went through, she’d been through it. She was a really good support. ... I think women support women best.*

*Tess: [My friend] was having a miscarriage. And she was phoning me for support for her miscarriage. She already had two children. [pause]. She knew that I’d been through fertility treatment with no children. The first person that she phoned for support when she was having a miscarriage of her third [living] child was me, the one that had gone through all that heartache for nothing. ... And what was awful*

*about that of course was that it triggered my own experiences and grief around miscarriage.*

**Katie:** *I have played that role for people, people that know that I've had a miscarriage and they think they might be experiencing one and they, like me, they don't know what to do. ... I did used to find that quite triggering.*

**Louise:** *I got really triggered [in a baby loss support meeting] by listening to a dad talk about his experience.*

**Tess:** *When you're in your time of need and you're vulnerable, and you want help, you want empathy from someone that knows what you've been through. How do you get that and how do you get it delivered in a way that's consistent and empathetic but also doesn't result in more harm to the person that's providing the support, too?*

Women who have been through miscarriage, and who 'get it', can provide valuable support for women experiencing miscarriage. Given we have heard the women speak about how their knowledge of miscarriage was sparse, and hard to find, and in the case of online information, often unhelpful and conflicting, it is no wonder there is a desire for connection with women who have lived experiential experience. However, due to silencing women may have few clear networks of support available to them. As discussed in Chapter One, while miscarriage is common, silencing can prevent women from knowing who in their social circle they can turn to for wisdom and support, constraining their ability to access support from women who 'get it'.

The women's conversation details how eliciting support from women with lived experience of miscarriage can place a heavy burden of care onto those women. We have heard that women's pain and grief of miscarriage continue to move through them in diverse ways, and have contested the 'endpoint' to pain and grief through contesting the construct of 'healing', and therefore placing the responsibility for support solely on women who are still

journeying through their experiences of miscarriage can open spaces for ‘triggering’ and further distress. “You want empathy from someone who knows”, says Tess, and I argue that the ‘knowing’ need not be confined only to women who have experienced miscarriage. If more spaces are opened to let women speak of their experiences, and for us to hear the complexity and diversity of those experiences, we can all come to ‘know’ miscarriage and share in a collective responsibility of responsiveness and care, easing the burden for women who may be suffering and still feel the flows of grief move through them. We can come to know miscarriage through opening spaces to listen to women’s stories, refusing to tolerate the expectation that stories of miscarriage be clean and sanitised, resisting the urge to ‘fix’ women or take away their pain, and instead embrace diverse stories of pregnancy, motherhood and loss that are confronting, messy and real.

### **The Collective Story of Miscarriage**

Bringing the women together to speak, from their standpoints as women who have lost babies to miscarriage, has enabled the telling of a more expansive, more diverse story of miscarriage and social support. Their voices join to grow our understanding of the messy complexity that is the experience of having a baby die during pregnancy, and how it feels to live with grief, with or without support.

Together, the women have spoken about how the social expectation for women to have children led them to question the point of their life and their worth, and undermined their sense of ‘womanhood’ in the wake of infertility and miscarriage. Furthermore, while the women were, and *are*, mothers, embodying and enacting motherhood through growing, loving, and cherishing their babies, the absence of a living baby in their arms meant they were often not socially recognised as mothers, as their motherhood and the existence of their babies was denied by others in a fundamental failure to recognise life and meaning.

The women have told us, together, that pervasive silencing denies spaces to honour their grief, pain and loss, and opportunities for connection and support. Left alone in the intensity of their feelings, women can question whether their emotional response to the death of their baby is ‘normal’. Furthermore, the silencing of miscarriage is remarkably at odds with the ‘indelible mark’ that miscarriage can have on women’s lives; we are failing to see and be responsive to what can be ‘life-changing’ for women.

Together, the women have told us of their suffering, and how they know what it means to suffer, and to be left to suffer, in ways unique to womanhood. We have heard their accounts of physical pain so mighty that they bit a mattress, screamed for their husband, feared for their life. The women have spoken of emotional pain and anguish, callously disregarded within a medical system that reduces ‘care’ to women’s physical bodies. We have heard stories of women’s suffering in the workplace, bleeding on a chair, on a towel, down their legs, and denied time off because ‘someone else has called in sick’.

Finally, the women have spoken together to reject the notion of healing, of ‘something good at the end’. While they may find themselves feeling ‘settled and content’, with living children or without them, their experiences of miscarriage and their grief will continue to move through them in diverse and complex ways. Together they have told us how powerful it can be to be ‘held’, to have people acknowledge the ‘happy-sad’ and to stay with them in the mess of grief with no expectation to be fixed, or fixable.

Now that we have listened to the stories the women wanted us to hear—now that we have received this gift of their embodied and experiential knowledge—we can, and must, ask ourselves: where do we go from here?

### **Conclusion: Growing Our Capacity to Care Through Connection**

I began this thesis with my story of miscarriage: a telling that was partial, situated, and too complex to fully speak of in one small passage. I felt both fearful and excited to tell my story. Fearful as I had not shared my story often with others, and was scared of exposing my pain, my grief and my vulnerability in a world that has not allowed me to easily tell my story of miscarriage, has not comfortably accepted or acknowledged my suffering. But I was also excited because I wanted to open a space for the telling, where you could see me in my grief and my suffering, hear what I needed and wanted, and maybe you would care about me, connect with me, share this space with me. I wish someone had shared their story with me—either before or during my journey of miscarriage—so that I might have felt that connection, might have known I was not alone, might have known how to ask for and receive the care and support I needed. As such, my hope at the outset of this research was to open spaces for more women's voices and stories to be heard, so that together we might begin a more expansive story of miscarriage and, consequently, grow our capacity to care.

### **Opening Spaces to Tell Stories**

Grounding this project in feminist standpoint theory and narrative inquiry has placed women's stories, voices and lives at the heart of this inquiry, privileging the situated, experiential, embodied wisdom of women who experience the death of their baby in pregnancy. As we listen to the stories of Joanna, Tess, Sara, Claire, Katie and Louise, we begin the journey of growing what we know of miscarriage, engaging narrative to open spaces for expansive and complex understandings of women's lives (Miller, 2017). Our hearing enables us to challenge assumptions of miscarriage as 'routine' or insignificant (Andipatin et al., 2019; Hardy & Kukla, 2015; Reinharz, 1988), and to engage with miscarriage as something weighty and complex, embedded in the diverse and shifting fabric of their lives. Stories of miscarriage are stories of motherhood, womanhood, (in)fertility,

divorce, medical trauma, distress, legacy, grief and love. As Joanna told us, the thing about miscarriage is that “there’s all this stuff that flows on through”. Through *The Listening Guide*, we were able to ‘tune in’ to each woman’s story through a mapping of the ‘landscape’ of her story (the plot), hear the way each she accounted for herself in her story (I poems), and engage with the complex interplay of her multiple (contrapuntal) voices. Being guided to listen in this way, while adopting a stance geared to possibility and potential, we have been supported to listen deeply and *differently*, coming to know and re-know the stories, and the women, enabling a ‘holding’ and ‘telling’ of the complexity and nuance of their stories.

Bringing the women together to ‘speak’ has enabled an expression of their collective standpoint through a “joining of partial views and halting voices” (Haraway, 1988, p. 590), offering an opportunity to further embrace the complexity of their stories by hearing the women ‘sing’ in harmony, or discordantly, or engage in a ‘call and response’. In chorus, they have spoken to, and resisted, the social and cultural forces that have silenced them.

We have heard these women’s stories now, although these stories are, of course, partial and limited (Bradbury, 2017; Haraway, 1988). Now our task, after listening to the women speak—both on their own and in chorus—is to ask ourselves: how do their stories open spaces for us to grow our capacity to care?

### **Embracing Mothers’ Grief**

Listening for real implores us to resist the medical gaze, where only the physical body is seen and, as such, treatment and ‘care’ becomes limited to the body and its biological components and processes (Lupton, 2012) and emotional and psychological aspects of care are disregarded or overlooked (Andipatin et al., 2019; Bellhouse et al., 2019). Moving away from reducing miscarriage to medical processes and entities, and towards honouring the existence of a mother and her baby, we start to see that significant and enduring grief and pain make sense: a mother’s baby died, so she grieves.

There is a need to recognise that a woman who is experiencing miscarriage is a human being going through an affective embodied loss. Her baby, with whom she has an enduring and meaningful relationship with, has died. 'Seeing' the mother means to acknowledge that she has both physical *and* emotional needs. Attending to her emotional needs requires seeing what she is going through, heeding the 'wild red flag', and choosing to provide sensitive and responsive care that dignifies her experiences. Choosing to use language that is sensitive to women's experiences, providing physical spaces within healthcare settings that do not augment women's pain, seeing and being responsive to women's embodied resistance, the provision of pathways that connect women to diverse forms of care: we have heard that *all* of these things are vitally important. Given space, women readily voice their wants and their needs, thus we need to continue to open spaces to hear and be responsive to those wants and needs. Currently, however, those spaces for hearing are constrained within our medical system, which is fragmented and inequitable, and lacks coordinated care and clinical pathways that can meet women's emotional needs (Yang et al., 2022). Acknowledging that transformation of our healthcare system is likely to be sluggish, there is an urgent need to expand and fortify webs of care within our communities.

Critically important, here, is the need to transform our social understandings of motherhood and mothers, resisting constrictive and harmful constructions of motherhood that deny the motherhood of women who miscarry, and opening spaces for expansive possibilities to honour motherhood in diverse forms. We have heard from the women that they *are* mothers; mothers with meaningful and enduring relationships with their babies. We can honour their motherhood by acknowledging, and legitimising, the grief that mothers feel when their babies die.

We need to recognise, become accountable to and resist how adept we are, in our society, at our turning *away* from the realities of grief, pain and loss. Choosing to insulate

ourselves from the grief and pain of others works to produce and re-produce the conditions for suffering and isolation for mothers whose babies have died. If we wish to ease suffering, rather than heighten it, it is vital that we acknowledge, respond to and dignify women's grief and pain, and open spaces for that grief and pain to be worked through publicly, rather than in isolation. This means imagining potentials for the 'making present' of grief and loss, finding ways, rituals and markers to honour pain and death through welcoming it into our social spaces in the present and making it part of our lives as we journey through.

### **Travelling Alongside Women as they Journey Through Miscarriage**

All of the women spoke of miscarriage as a pivotal 'event' in their lives. The notion of miscarriage as enduring and life-changing challenges our 'medicalised story' that positions miscarriage as an insignificant, acute, biological (non)-event that is 'for the best' (Andipatin et al., 2019; Hardy & Kukla, 2015; Reinharz, 1988). A woman's story of miscarriage does not end when the medical event of miscarriage is over. Instead, we have heard how losing a baby during pregnancy can be the start of a journey that will unfold across the lifespan in diverse ways. Miscarriage as an experience continues to move through women as they venture forth carrying with them their grief, traces of the trauma, and diverse forms of enduring connections with their babies.

Given the significance of miscarriage for women, we need to recognise the impact that experiencing miscarriage can have on the way women relate to and engage with their social world, as mothers who are grieving. We must open possibilities for responsive care where we see and meet women in the messy complexity of their grief and pain. By 'staying the journey' with women, we can support them to continue to relate to and engage within their social worlds without the need for withdrawal.

Choosing to turn towards, and stay with, pain, we must then resist the urge to try to 'fix' that pain. Coming to know grief when your life takes a sharp turn and your baby dies is a

messy, complex and painful experience that we should not demand women to ‘heal’ from. Providing empathic and responsive care means to be willing to sit in and embrace the ‘mess’ of grief with women, meeting them where they are and honouring their pain as real and meaningful. Resisting notions of healing as a ‘end point’ to women’s stories of miscarriage is vital if we are to recognise that miscarriage experiences, and grief, will continue to move through women in diverse and enduring ways. Therefore, the care and support we provide must be dynamic and capable of meeting women where they are, responsive to the shifting landscapes of women’s lives.

### **Support Through Connection**

As communities, transforming the way we care for women who miscarry means becoming accountable to women’s pain and suffering, and stepping into our collective responsibility to one another. We must not rely on women who are grieving the loss of their babies to take on the responsibility and burden of caring for other grieving women. Acknowledging that women’s pain and grief can be heavy, and deserves space to be worked through, we can all become accountable by sharing in the responsibility of caring for women in pain. Through redefining our “sense of attachment and connection to a shared world” (Braidotti, 2013, p. 193) we can move toward imagining and realising possibilities and potentials, and commit to ‘doing better’.

Listening paves the way for these possibilities and potentials; we have *so* much to gain by listening. The women’s stories have shown us that the telling of stories enables connection, and the possibility of connection *through* diversity if we open ourselves to hearing stories. Through opening spaces for diverse stories to be told, and through listening, we can all ‘come to know’ miscarriage, in all its messy complexity and nuance, knowing that for each woman her experience of losing her baby during pregnancy will matter, and make sense, in unique and meaningful ways. By listening to the imagining of possibilities and

potentials that flow from the wisdom of women who endure the pain, suffering and grief of miscarriage we can become those people that 'get it', the 'someone that knows', even if we have not personally lived miscarriage. Through deepening our understandings we can deepen our connections, and it is from this place that we can learn to do and be better. Telling and hearing stories not only breaks the silence, but enables empathy that can mobilise and grow our capacities for care.

### **Openings Spaces to Tell More Stories**

Within the scope of this research I have been able to listen to, and share, the voices of just six women alongside my own. There are many more stories, and untold stories, of miscarriage to be heard. I reflect on my recruitment stage, when I spoke to a friend who told me that she would not want to participate because her experience was 'good', expressing her hope that I would find a range of participants so that I heard more than 'good' experiences. I got the sense that she knew other women suffer, and she did not want her 'good' experiences to overshadow theirs. We can pause here to ask: what is there to learn from women who have 'good' experiences of miscarriage support? Their stories are worthy of space to be heard, too, and hold such possibility and potential for teaching us better ways of responding to, caring for and supporting women who experience miscarriage. We should seek out these stories from women who had 'good support' so that we can learn from them how that support met their needs and wants, and the impact this can have.

Equally, it is on all of us to not hear one 'good' story and assume that women breeze through miscarriage, unaffected. We must honour the diversity of stories. I am aware that my recruitment method has narrowed the diversity of stories for this project, restricted by geographic location and my own networks of predominantly Pākehā, middle class, women. The knowledge we have heard is situated, of course, and largely rooted in Western, neoliberal understandings of what miscarriage can be, and how it is experienced, responded and related

to. The stories told by the women, and by me, merely scratch the surface. We need to listen to more voices, and seek more diverse stories.

The women's stories were complex and expansive, and within the boundaries of this research my capacity for 'telling' was limited, regrettably leaving many aspects of the stories untold. Yet, now I move on, carrying these complex stories with me, my horizon of understanding expanded and enhanced in ways I will never be able to bring to the page. These stories have grown the story that I knew, and they will continue to move through me in diverse ways, shaping the way I relate to and care for those around me. And I wish this for all of us, as communities of people who care, to have our understanding of miscarriage expanded and enriched, to increase our capacity for care and to heed, never turning away from, the 'wild red flag'. I want us to know that it is ok not to say the 'right thing', it is ok that we cannot 'fix' women's pain, it is ok that this is sad and overwhelming and complex. I want us, in the face of the 'messiness', to find ways to connect—a hand on the shoulder, a cup of tea, a phone call—in order to let women know we see them as mothers, we see their grief for their babies, and we will stay here with them.

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## Appendix A: Participant Information Sheet



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### Women's experiences of social support after miscarriage in Aotearoa

#### *Participant Information Sheet*

##### **Researcher introduction**

Tēnā koe. My name is Rosie Rooney. I am undertaking this research for the fulfilment of the requirements for a Master of Arts degree in Psychology, under the supervision of Dr Stephanie Denne from the School of Psychology at Massey University. I live in Wellington and am a full-time student.

Please feel free to contact either myself or Stephanie by phone or email if you have any queries about this research. You'll find our contact details near the end of this information sheet.

##### **Project Description**

Miscarriage is very common, occurring in about one or two out of every 10 pregnancies; however it can be significant, impactful event in a woman's life. The silence that surrounds miscarriage, and the fact that often it is not often talked about openly, can leave women feeling isolated and alone as they come to terms with their loss. Good social support can enhance wellbeing and coping after miscarriage; however seeking out and accessing support can be challenging. This research aims to provide a deeper insight into the lived experience of miscarriage in Aotearoa through exploring women's experiences of social

support after miscarriage and how women believe social support can be improved. This will be achieved through listening to the stories, experiences and feelings of women who have experienced miscarriage, told during a non-judgmental and confidential interview with me. Interviews will then be analysed to identify narratives of effective social support practice and possibilities for improvement in the provision of care for women and their whānau.

### **Participant Identification and Recruitment**

To take part in this research you must meet the following criteria:

- Identify as a woman
- Be aged 18 or over
- Currently be living in Wellington
- Feel comfortable speaking and communicating in English
- Have experienced at least one miscarriage (a pregnancy that ends on its own, up to 20 weeks' gestation)
- It must be at least two years since your most recent pregnancy loss (miscarriage, stillbirth or ectopic pregnancy loss) or child loss (neonatal, infant or child).

I will be recruiting 8-12 participants through asking trusted intermediary contacts to provide this information sheet to women who they think may be interested in participating. An intermediary contact has provided this information sheet to you because they think you may be interested in participating. They do not need to know if you choose to contact me and I will not tell them if you contact me. Please read and consider this letter carefully before you think about whether you would like to participate.

If you are interested in participating in this study you will first be invited to meet me, Rosie, either online over Zoom or in person, to discuss the research in more detail and to address any needs you may have, including support, cultural considerations, COVID-19 safety standards and childcare. I will be happy to answer any questions you have. This initial discussion should take no longer than 30 minutes. If you would like to proceed as a participant, an interview date and time will be negotiated, and you will be provided with an written informed consent form which will need to be signed and returned before the formal interview.

**What this study will involve:**

The formal interview will take place either online using Zoom, or in-person - whichever you prefer. The location for in-person interviews will be mutually decided, with consideration for your safety, convenience and comfort. You will be provided with key interview questions and themes in advance, so you have time to consider them before the interview takes place. The interview will take approximately 60-90 minutes to complete; however, there will also be an opportunity to extend the time if you would like to continue the interview. You will receive a \$20 grocery voucher as appreciation for your valued contribution to the research.

Talking about experiences of miscarriage and support may raise thoughts or feelings that can be uncomfortable, so I will set aside time at the end of the interview to debrief and check in with how you are feeling. You are also welcome to bring a support person, support people or whānau with you to all of our meetings together. Each support person or whānau member will be asked to sign a form which outlines confidentiality and expectations of being a support person. Details for local support agencies are listed near the end of this information sheet; some forms of support are free to access, while some of the counselling services incur a cost which would be your responsibility. I cannot contact the support agencies for you. However, I can support you to contact an agency by being present during the phone call or providing a phone for you to make the call.

**Covid-19 Safety Standards**

This research project complies with Government guidance for science and research during the COVID-19 pandemic and meets all national requirements to manage public health measures and existing WorkSafe practices.

**Project Procedures**

Should you decide to participate, it is important you have a clear understanding of the research purpose and process. This will be carefully explained to you in the initial meeting. Participation in this research is confidential and your privacy will be protected. You will be provided with a written consent form which will need to be signed before the formal interview. If you consent, the interview will be digitally recorded and stored on a password-

protected device and then deleted after I transcribe the data. Zoom interviews will require both image and audio recording, and I will destroy the image recording as soon as the interview is complete, retaining the audio recording for transcription - after which it too will be destroyed.

I will transcribe the interview myself into a written digital format and I will remove all identifying material at this point. When this is complete, you will be offered the opportunity to read and make edits to the transcript, which should take approximately 30 minutes. With your final approval of the transcript, I will ask for you to sign a Transcript Release Form. The choice to participate is voluntary and you can withdraw from the study at any point up until the transcript has been released for analysis.

My supervisor will keep consent forms and transcriptions stored securely for five years and then they will be destroyed. Only myself and my supervisor will have access to the consent forms and transcripts.

Once the research is complete, if you have expressed interest in the outcome of the study, I will contact you to provide a written summary of findings, or an opportunity to meet face-to-face (in person or online) to discuss findings and to provide feedback about your experience of participation. I will prepare a summary of the research outcomes to provide to organisations in Aotearoa who support women and whānau after miscarriage and other forms of baby loss, including Sands NZ and Vicki Culling Associates, and may seek to share findings through academic publications and presentations.

Overall, participation should not require more than 3 hours of your time, including the initial meeting, the formal interview and transcript review.

### **Limitations of Confidentiality**

The information obtained in this study will be treated confidentially. However, if there is a situation in which I have serious concerns for your or someone else's wellbeing, I may need to contact my supervisor, your support person or a support agency. In this situation I would stay with you until your safety has been established.

### **Participant's rights**

Participation is voluntary and you are under no obligation to participate in this project. If you decide to participate, you have the right to:

- bring a support person/support people/whānau with you to each meeting;
- ask any questions about the study at any time during participation;
- decline to answer any particular question;
- ask for the recorder to be turned off at any time during the interview;
- have time to read, consider, discuss and edit the transcript prior to analysis;
- provide information on the understanding that your name and identifiable information will not be used;
- withdraw from the study at any point up until transcript release;
- be given access to a summary of the project findings when it is concluded.

Thank you for taking the time to consider participation in this research. Participation is confidential and voluntary. If you would like to discuss this research further with me, please get in touch via email, phone or text and we can arrange a time to talk.

Ngā mihi nui

Rosie Rooney

### **Project Contacts**

Rosie Rooney, 020 4112 4243, [rose.e.rooney@gmail.com](mailto:rose.e.rooney@gmail.com)

Stephanie Denne, 06 356 9099 ext. 85082, [s.denne@massey.ac.nz](mailto:s.denne@massey.ac.nz),

*This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 22/41. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800, x 43347, email [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz).*

## Support Agencies

### *Sands New Zealand*

Sands New Zealand are a national volunteer-run non-profit organisation who support parents and whānau who experience the death of a baby at any stage during pregnancy and after birth. Sands offer safe opportunities and environments to connect with other bereaved parents and to share experiences, stories and feelings. They host regular local in-person support groups across Aotearoa, as well as regular online support groups, including “Empty Arms” meetings for bereaved parents with no living children.

They also host private online support groups on Facebook, which are spaces to chat and korero to other bereaved parents and to listen to and tell stories of loss.

To access Sands online support groups on Facebook search the group names and request to join the private group:

- *Sands New Zealand Bereaved Whānau Chat*
- *Sands New Zealand Bereaved Whānau Information Page*
- *Sands NZ Bereaved Dads Chat*

Website: <https://www.sands.org.nz/>

Contact details for localised support groups, and for local meeting days and times can be found at [www.sands.org.nz/supportgroups.html](http://www.sands.org.nz/supportgroups.html)

### *Little Shadow*

Little Shadow offer counselling, support and information for anyone experiencing perinatal distress. Perinatal means anything to do with pregnancy, birth and early parenthood, and includes miscarriage, baby loss and infertility. Little Shadow counsellors are professionally trained and committed to providing safe, non-judgmental support. Counselling services are subsidised and start at \$55 per hour, and are available in-person at various locations in the wider Wellington region or online. Counselling sessions can be booked via the Little Shadow website.

Website: <https://www.littleshadow.org.nz/>

Email: [hello@littleshadow.org.nz](mailto:hello@littleshadow.org.nz)

***Vicki Culling***

Vicki Culling is a leading advocate, support provider and educator in the baby loss community in Aotearoa. She is a bereaved parent herself, and worked with Sands NZ at both local and national levels for over 15 years. She is experienced at providing support for bereaved parents and whānau, running both online and in-person support meetings for Sands NZ, as well as advocacy work through her own organisation, Vicki Culling Associates.

Vicki is supportive of this research project and has offered a one-on-one support session to participants in this research in the event that participation raises feelings of discomfort for participants that lead them to require additional support. Vicki can be contacted by email or phone (text or call) to arrange a support session.

Website: [www.vca.co.nz/](http://www.vca.co.nz/) Email: [vicki@vca.co.nz](mailto:vicki@vca.co.nz) Phone: 021 776 436

***1737***

You can call or text 1737 at any time to talk to a trained counsellor or peer support worker. This service is completely free. The support offered is brief 1:1 counselling, and can include referral to another service or additional counselling.

## Appendix B: Participant Consent Form



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#### *Participant Consent Form*

I have read and I understand the Participant Information Sheet provided. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any point until my transcript has been released for analysis.

1. I agree/do not agree to the interview being sound recorded.
2. I agree/do not agree to the interview being image recorded, understanding the image recording will not be used in the study and will be destroyed immediately after the interview.
3. I wish / do not wish to have my recordings returned to me.
4. I wish / do not wish to nominate my own support person(s) or whānau member(s) to be present during the interview.
5. I wish / do not wish to access a summary of the project findings when the project concludes.
6. I agree to participate in this study under the conditions set out in the Participant Information Sheet.

#### **Declaration by Participant:**

I \_\_\_\_\_ hereby consent to take part in this study

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix C: Participant Interview Guide



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#### *Participant Interview Guide*

Tēnā koe. Thank you for agreeing to participate in this interview. I am interviewing you to better understand how women in Aotearoa experience social support after miscarriage, and how they feel social support could be improved. There are no right or wrong answers to any of the questions - I am interested in your own experiences. As detailed in the Participant Information Sheet, you have the right to decline to answer any question during the interview and to ask for the recording to stop at any time.

This guide only represents some questions that may be asked and the main themes that will be discussed. All of the questions below will not necessarily be asked during the interview. Various prompts may also be used, such as, "Can you please tell me a little bit more about that?" or "What was that like for you?".

#### **Interview themes**

- The experience of social support after miscarriage
- Key people in the support network after miscarriage
- How social support after miscarriage could be improved

#### **Possible interview questions**

*Can you tell me about your experience of social support after your miscarriage(s)?*

*Who did you seek support from after your miscarriage?*

*What suggestions can you offer for how social support can be improved after miscarriage?*

*Is there anything else you would like to tell me that we have not covered?*

## Appendix D: Participant Health And Safety Support Plan



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#### *Participant Health and Safety Support Plan*

Relationships and interactions with participants will be guided by values of aroha and manaakitanga and in alignment with the ethical principle of non-maleficence, strategies to minimise and respond to discomfort will be engaged.

Steps will be taken to mitigate potential discomfort for participants. During the initial meeting I will explain what to expect in terms of interview content and process. I will discuss key interview questions and themes and will also provide them in written form (Participant Interview Guide) prior to the formal interview, to allow participants to consider responses in advance and to minimise the threat of any unpleasant or surprise questions. I will ensure participants feel prepared for the interview and that they feel ok to discuss the topic at length.

I will ensure the formal interview environment is warm and secure, and that power differentials between researcher and participant are minimised by conveying a non-judgmental attitude and spending time easing into the interaction, getting to know them, and helping them feel comfortable before the interview begins. The interview will be participant-led, allowing the participant as much control as possible and letting them tell their story in their own words and order and at their own pace. I will reinforce to participants that they may request a break or conclude the interview at any time.

During the interview participants may experience discomfort as they recount and reflect on their experiences. I will monitor participant's emotional reactions, body posture, tone and language, being watchful for signs of discomfort such as disengagement, dissociation,

difficulty speaking or appearing uneasy, tense or agitated. Should signs of discomfort be noted I will pause the interview and suggest a break, check in with them about how they are feeling, and will spend some time talking with them until either the discomfort passes and the participant indicates they are willing to continue, or I will conclude the interview and initiate support.

At the conclusion of every interview, I will turn the recorder off and debrief the participant. This will proceed in an unrushed manner and will involve checking in with them and spending time bringing them back to present. I will ask the participant how they are feeling and how the interview went for them, acknowledging and validating emotions and feelings that may have arisen during the interview. I will talk through support resources provided with all participants and ensure that they have the means to contact support agencies if required. Should a participant indicate that they need support to cope with feelings of discomfort that arise during or after the interview, I will support them to make a plan to access support. Support agencies include SANDS NZ, a national organisation providing information and support for women and whānau who experience baby loss, and Little Shadow, who provide counselling and support for people experiencing perinatal distress. Participants will also be offered free one-on-one, face-to-face online support with Vicki Culling, a highly experienced support provider and educator within the baby loss community in Aotearoa.

Should a situation arise where a participant presents immediate danger to themselves or someone else, support for the participant will be sought from a support person known to them, the woman's GP, a crisis support team if required, and my supervisor will be engaged to advise and assist with facilitation of support. I will stay with the participant until support has been accessed.

I will always have my cell phone on me and the contact number of my supervisor, who will know in advance that each interview is taking place and will be available to respond to any issues that arise. I will ensure my own availability extends beyond the expected timeframe of the interview, so that I can provide support for the participant should they require it after the formal interview is complete.

## Appendix E: Support Person Confidentiality Agreement



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#### *Support Person Confidentiality Agreement*

Tēnā koe,

Thank you for offering your support to the participant in this study. The information shared within this conversation is private and confidential to the participant. No other people, aside from the researchers, will be aware your friend has participated in this research. It is important your friend feels they can share information they may otherwise keep private. If your friend is agreeable, you can discuss with them what they talk about; however, please keep this information to yourself.

The formal interview will be digitally recorded, and the digital recording will be destroyed after the interview has been transcribed. Anything you say during the interview will not be transcribed.

By signing this document, you agree to maintain the privacy and confidentiality of the person you are supporting in this study.

Declaration by Support Person:

I \_\_\_\_\_ agree to maintain participant privacy and confidentiality.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix F: Transcript Release Authority



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#### *Authority for the Release of Transcripts*

I confirm that I have had the opportunity to read and amend the transcript of the interview conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

**Signature:** ..... **Date:** .....

**Full Name (printed)** .....