

EXEGESIS

**Researching and Writing
'A Hospital Bed At Home'**

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Chapter One

INTRODUCTION

This exegesis discusses my creative work, 'A Hospital Bed at Home' in terms of context and process. I begin by presenting academic, instructional and auto/biographical literature about home-based palliative care, to provide useful background information and to underline the significance of this topic. Secondly, I develop a conception of my project as a biographical type of life writing within the field of narrative inquiry, with an investigation of lived experience culminating in creative nonfiction stories as a research outcome. This then leads into a consideration of the ethics of life writing, particularly the question of how to strike an appropriate balance between the interpretive authority of the creative nonfiction writer and the ethical treatment of the informant whose experiences are being pinned to the page. Finally, I give a full exposition of the processes behind the production of the manuscript, including theoretical and practical details regarding epistemology, methodology, conduct, ethical decisions and outcomes.

In Australia, we live in a society with an ageing population in which the incidence of life-threatening chronic disease is rising (Australian Bureau of Statistics 2009; Palliative Care Australia 2010). Although much of the caregiving in the final year of life will take place at home, involving considerable commitment from a family member or friend (Hudson 2003b), 79% of Australians admit they know almost nothing about palliative care (Palliative Care Australia 2006). Like me, many will find themselves thrust into a demanding and stressful role with minimal information and no previous experience, and research shows that all too frequently they will struggle, from love and a sense of duty, to fulfil this role despite its adverse affects on their own physical, psychological, emotional, social and financial well-being (Grbich, Parker & Maddocks 2001; Palliative Care Australia 2004).

My motivation for undertaking this project was to explore questions that had lingered with me even after my own time as a caregiver had ended in November 2006. These questions came from a sense that I had somehow failed

to rise to the occasion, despite my best intentions. I needed to find out how other people coped with the challenge of caring for someone who was dying at home. I wanted to make sense of my own experience, and also to find out what others brought to the role of caregiver, what got them through it, and how the experience impacted on or reflected the relationship between themselves and their patient. I also felt that a collection of insightful, engagingly written stories about home-based palliative care would be useful. I hoped it would be a supportive resource for family carers, depicting and validating their experiences; and I hoped it would serve to increase understanding and empathy about their situation among health professionals, policy makers and the general community.

I brought to this project my personal experiences in the form of a day-by-day record of what I had done, thought and felt. Writing in my diary, sporadically from May 2003 when my mother's breast cancer shockingly recurred after a hiatus of more than five years, and then extensively from June 2005 onwards, when brain tumours sent her into a pitiful decline, had been one of my principal coping mechanisms. This first-hand immersion informs not only my own memoir, which is the final story in the collection, but also provided the base level of understanding that I brought to the task of writing the other stories as well.

Another aspect of my background that shaped how I approached this project was a longstanding interest in the philosophy of science and in qualitative social science research methodology. My undergraduate major was philosophy (and computer science) and my research Masters degree used interpretive case studies to explore relationships between small business owners and consultant web site developers. This experience as a qualitative researcher primed me to have a particular interest in the ethical conduct of research. When I sent my case study narratives to participants for verification, one of the consultants rang me to complain that I had depicted him in a way that could be damaging to his professional reputation. During our wide-ranging, semi-structured interview he had told me that doing web sites was an adjunct to his primary interest in small business coaching, and that he saw web site development as a way of getting 'in the door' so he could offer broader types of advice and support. This unguarded statement – an example of the "enough rope" principle in operation – was integral to my account. Should I, nonetheless, have offered to remove it, rather

than responding that I had quite accurately reported what he had said? Even now, I am not entirely sure.

The issue of who should exercise interpretive authority when writing lives is one that has been debated extensively by theorists, practitioners and critics from within auto/biography, narrative inquiry, journalism and creative nonfiction. Examples abound of life writing causing harm by deliberately or inadvertently impinging upon the subject's privacy, reputation or sense of self (Couser 2001; Donaldson, Read & Walter 1992; Eakin 1999). However, interpretive independence and writerly integrity are ideals fiercely upheld by biographers, scholars and journalists alike, who all quite rightly seek to avoid producing work that is hagiographic, superficial or dishonest (Bloom 2003; Chase 1996; Malcolm 2004; Pybus 2000).

Consideration of how conflicting loyalties and competing values can create moral quandaries in which the author's rights are pitted against the subject's rights led me to the research problem at the heart of my thesis (both the creative work and the exegesis), which was determining how to deal with the ethical tensions involved in telling a story about someone else's life in a way that would not hurt, exploit or misrepresent them, while still telling it in a way that would preserve my integrity as the writer of that story.

As I explain in the following chapters, the solution I adopted was to make certain decisions regarding consultation and negotiation with participants. Some of these decisions were incorporated into my research design and articulated in the documentation I gave to participants; some of them had to be developed as the research proceeded. Throughout, I tried to take a non-exploitative, non-maleficent approach to the task of producing non-superficial, non-rose-tinted, nuanced accounts of home-based palliative caregiving. The result is manifest in both the manuscript 'A Hospital Bed at Home', and in the detailed account of processes and outcomes contained in this exegesis.

Chapter Two

LITERATURE REVIEW

The first part of this chapter places the project in its context by providing definitions of palliative care and family carers and discussing the literature relating to home-based palliative caregiving. I then explain my personal motivations for exploring this topic, and develop a conception of my project as a biographical type of life writing within the field of narrative inquiry, with an investigation of lived experience culminating in a suite of creative nonfiction stories as a research outcome. Finally, I discuss the ethical issues involved in using lives as fodder for writing.

Palliative Care

Palliative Care Australia, the national peak body for palliative care organisations, estimates that each year 64,000 Australians die an “expected death” from a terminal illness, and one in three Australians have had someone close to them die from a terminal illness in the past five years (Palliative Care Australia 2006). However, despite the broad impact of terminal illness on the general community, a Newspoll survey in May 2006 indicated that 79% of Australians knew little or nothing about palliative care (Palliative Care Australia 2006).

Palliative care involves the provision of specialised, multidisciplinary health care services when it is recognised that a person has an active, progressive illness with little prospect of cure and the primary treatment goal is the best possible quality of life for patient and family (Masso et al. 2004). Most commonly, the progressive illness is cancer, however it may also be motor neurone disease, HIV/AIDS or end stage heart, lung or kidney failure. Palliative care is not just about end-of-life care: ideally it commences soon after diagnosis of a terminal illness, with the aim of relieving symptoms, managing pain, helping the patient to live as actively as possible, and supporting family members and caregivers (Palliative Care Australia 2007). In brief:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization 2007).

Of course, definitions such as these represent an ideal state and there is cause to believe that palliative care as it is actually practiced is somewhat different.

Kellehear (2001) laments the fact that in Australia, palliative care does not begin at diagnosis, but is largely restricted to the final three to six months of life and emphasises the physical care of the patient. Good palliative care is supposed to include emotional, psychological and spiritual dimensions of care, covering the whole family; however, focus group data collected by Grbich, Parker and Maddocks (2001) showed that palliative care health professionals see their role in terms of pain management, personal hygiene, equipment supply and advice. Emotional care was an area where the health professionals reported having 'minimal skills and maximal discomfort' (Grbich, Parker & Maddocks 2001, p. 36).

Family Carers

In Australia, Palliative Care Units based in hospitals provide beds for patients with symptoms requiring treatment or stabilisation, or patients needing temporary respite care or end-of-life care. Consequently, whilst families may be receiving services and resources through linkage with a Palliative Care Unit, there is an increasing trend for caregiving to take place at home (Hudson 2003b). Although fewer than one in three anticipated deaths takes place outside an institution (hospital, nursing home or hospice), up to 90% of terminally ill patients spend most of their last year at home (Home Hospice 2008; Hudson 2003b; Palliative Care Australia 2004). Home-based palliative care and indeed, home death, have been confirmed by many studies as the preferred option for the majority of people with a terminal illness, and this preference is compatible with the government's objective to shift health care into the community; however, it depends upon considerable commitment from family caregivers and friends (Foreman et al. 2006; Home Hospice 2008; Hudson 2003b; Palliative Care Australia 2004).

The Australian Bureau of Statistics defines a primary carer as someone ‘who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities...for one or more of the core activities [of] communication, mobility and self care’ (2004, p. 77). In 2003, there were 2.6 million carers in Australia; about one-fifth of these were primary carers (Australian Bureau of Statistics 2004). Carers contribute more than \$20 billion a year in unpaid work to the Australian economy and provide 76% of all services to people needing care and support (Palliative Care Australia 2004). Tasks commonly undertaken by carers include: managing medications and liaising with health professionals; assisting with personal care related to bathing, dressing, eating, moving around and toileting; performing household tasks like washing and cooking; providing transport; managing finances and providing emotional support and companionship (Briggs & Fisher 2000).

Primary carers are predominantly female (71%) and live with the care recipient (78%). Most are middle-aged (35-64 years). Primary carers have a lower labour force participation rate (39%) than people who are not carers (68%) and 37% of them spend on average 40 hours or more per week providing care (Australian Bureau of Statistics 2004). In palliative care, two-thirds of caregivers are wives and one-fifth are daughters or daughters-in-law (Palliative Care Australia 2004).

Literature on home-based palliative caregiving

In the discussion that follows, I divide the literature on palliative caregiving into three groups and consider each in turn, paying most attention to the first and third as they most closely relate to my own work. The categories are these: research reports; practical, instructional material; and auto/biographical accounts of caring for particular people.

The topic of home-based palliative care has received substantial international academic attention over the past decade (Andershed 2006; Broback & Bertero 2003; Duhamel & Dupuis 2003; Goldstein et al. 2004; Grbich, Parker & Maddocks 2001; Hudson 2003b; Payne, Smith & Dean 1999; Scott, Whyler & Grant 2001; Stajduhar 2003; Strang & Koop 2003; Wennman-Larsen & Tishelman 2002; Zapart et al. 2007). Much of this research explores the stressful

and demanding aspects of the role and indicates an urgent, unmet need for better recognition, support and information for unpaid carers. The adverse impact of the caring role can be summarised in terms of the effects it has on carers' physical health (disturbed sleep, exhaustion, injuries); psychological health (stress, depression, anxiety, grief, frustration); and life opportunities (financial difficulties related to curtailment of employment; social isolation; limited time for pursuing own activities). In a national survey conducted by the Carers Association of Australia (Briggs & Fisher, 2000), 58% of the 1,449 respondents reported that their health was worse as a direct result of caring; a third said they had sustained at least one physical injury in performing their caregiving tasks (most frequently a strain or sprain of joints or muscles); more than half reported depression, anxiety, high levels of stress and other detrimental effects on their own mental and emotional wellbeing, and nearly 60% experienced major negative effects on their life opportunities, especially travel, pastimes and paid work. Diminished personal and leisure time due to caregiving responsibilities reduces engagement in outside activities and social isolation may ensue. In fact, some carers become as housebound as their patients (Hudson 2003b). In a study of 750 carers of cancer patients, 62% reported feeling that they had to be available 24 hours a day (Barg et al. 1998).

Counterbalancing the litany of burdens is evidence indicating that caregiving can also invoke strong positive emotions related to expressing love and feeling pride in a job well done. Case study research conducted in Adelaide, involving 20 carers of terminally ill family members, found that:

The gift of time, and the pleasure of being given the opportunity to communicate one's love and to show affection through care were emphasised. When the patient was able to respond and to appreciate this love, much of the negative emotion experienced was alleviated and the caregiver's self-worth heightened. Considerable pride was expressed that, despite all the difficulties faced, most caregivers felt they were doing a good job and were proud of their capacity to manage in the face of minimal information, limited service provision, and no previous experience (Grbich, Parker & Maddocks 2001, p.35).

A qualitative study of 47 family carers of advanced cancer patients in Melbourne found 60% readily identified positive aspects of the role as well as aspects they found challenging or burdensome (Hudson 2004). Key challenges were the caregivers' own ill-health, concerns that they lacked the necessary skills to manage the patients' symptoms, lack of support from health care professionals,

the stress of watching their loved ones deteriorate, and having no time for themselves. The researcher postulated that caregivers used positive interpretations of the situation to buffer the challenging aspects and to enhance and maintain their coping resources. Positive comments from the carers included: 'I feel like I'm a stronger person now'; 'It's nice to have her at home to be able to talk with each other and share precious time'; and 'We have become closer through this experience' (Hudson 2004, p. 62). However, the remaining 40% of carers were adamant that there were no beneficial aspects at all: 'No, the whole thing's a nightmare'; 'I don't know how anyone could see it as a privilege [caring for her husband] – it's a horrible thing'; and 'No – we've always been close, there are absolutely no positives associated with this situation' (Hudson 2004, p. 62).

In mid-2003, Palliative Care Australia conducted a national inquiry into the social impact of caring for terminally ill people and produced a report that gathered together current policy and research plus a wide range of experiences and opinions (Palliative Care Australia 2004). The report, titled *The Hardest Thing We Have Ever Done*, comprises two parts. Firstly, a review of the literature, highlighting the challenges and difficulties faced by unpaid carers. Second, an analysis of the public submissions from individual carers, service providers and support organisations, from which the following conclusions are drawn:

The picture that emerges from the public submissions is that carers for dying people 'make do' with whatever information and support is available to them or comes to their attention, should they happen to be at the right place and at the right time, or have the know-how to navigate the system. Those fortunate to have sufficient support mostly feel positive about their caring experience, while those less fortunate undertake caring responsibilities at the expense of their physical, emotional and financial wellbeing. The experiences of carers suggest that a considerable amount of service contact/access occurs on a random or ad-hoc basis (Palliative Care Australia 2004, p. 8).

The report noted the particular disadvantages faced by carers in rural areas: the lack of appropriate services available locally, the financial and practical burdens associated with having to relocate to metropolitan centres for specialist treatment, and the difficulty of obtaining expert advice and access to respite and other support services upon returning home. In its conclusion, the report stated there was 'compelling evidence to indicate that the work of carers is undervalued

and marginalised in the Australian community' (Palliative Care Australia 2004, p. 62) and recommended 'education at a community level, to promote the social value of caring and an awareness of the demands and impact of the caring role' (Palliative Care Australia 2004, p. 7). Since then, Palliative Care Australia has been involved in addressing this need for greater community awareness via media releases and activities during National Palliative Care Week, community service advertisements on television, and by providing information resources and personal stories on its web site www.palliativecare.org.au. Carers' associations at a national and state level are also working to build awareness of carers' needs and representing their interests through research, policy submissions, advocacy and publications.

Carers NSW has extensive, generic "how-to" information about being a carer on its web site www.carersnsw.asn.au, including a carer support kit (available in English and thirteen other languages) that contains fact sheets about legal arrangements, respite care, loss and grief, managing medications, managing money, and taking care of yourself. Many carers have published books based on what they learned while looking after loved ones with particular diseases; for example, *Copping it Sweet: A handbook for Australian carers* (Buchanan 2007), about caring for relatives suffering mental illness, and *Remember Me, Mrs V? Caring for my Wife: Her Alzheimer's and others' stories* (Valenta 2007). A quirky one from Great Britain is *The Selfish Pig's Guide to Caring* (Marriott 2006), a humorous, irreverent look at some of the taboo subjects of caregiving, including resentment, sexual frustration, incontinence and the occasional desire to push your loved one down the stairs, written by a man whose wife deteriorated over many years from Huntington's disease. Far more textbook-like in tone and content is the *Carer's Handbook: A practical Australian guide to caring for people who are sick, elderly or have a disability* (Carers Australia 2007), published in conjunction with St John Ambulance Service and marketed as 'a fully illustrated guide for those looking after someone at home, with comprehensive advice on all aspects of caring', including step-by-step photographs illustrating ways of carrying out daily tasks, such as moving someone safely. Finally, a book that specifically addresses carers who are tending a dying family member is Michael Barbato's *Caring for the Dying* (2002). Written by a doctor with forty years of experience in palliative care, the

book is not only a fount of clear, useful information about practical matters, it is also a thoughtful, insightful guide to the psychosocial and emotional aspects of caring for people as they are dying.

Crossing Over: Narratives of palliative care (Barnard et al. 2000) straddles my three categories of academic, instructional and biographical palliative care literature. It is based on primary research, was written to inform trainee health professionals, and contains detailed stories about particular patients, families and caregivers. True stories written by or for health professionals about the intricacies of the end of life experience are increasingly recognised as a valuable research tool (Bingley et al. 2008). The authors of *Crossing Over* used participant-observation and in-depth interviews to produce ‘extended, richly detailed, multiperspectival case narratives...well suited to portray the physical, psychological, spiritual and social dimensions of terminal illness, the dynamics of the caring relationship, and how all of these are woven together and interact with each other’ (Barnard et al. 2000, pp. 6-7). Each narrative is about twenty pages long and traverses the biographical and medical background of the patient and the clinical course of the illness, as well as including perceptions of the unfolding situation from the patient, their family and their health care providers. They are written in the third person, and in order not to disrupt the narrative flow, commentary and discussion questions about the issues raised in each one appear in the supplementary section of the book. Without explicitly labelling their work as creative nonfiction, the authors acknowledge their own subjectivity in shaping the stories that they tell:

Of course, the narratives in this book are *our* stories, told in *our* voices. In order to transfer the rich, sometimes overwhelming details of many people’s experiences into a single narrative, we have had to be selective. We have imposed our sense of theme on experience, which in its pure state has no theme but simply follows the continual flow of life. We have often resorted to devices of narration, scene-setting, and similar features typical of fiction. These narratives are works of fiction in the sense that they are the result of creative, selective, shaping processes that are inherent in all storytelling. We do not present them as the definitive, “objective” story, “the way it was”. On the other hand, we have tried to be as faithful as possible to what we witnessed, and we have tried to situate our observations and our identification of themes in the larger context of other empirical and narrative research on palliative care (Barnard et al. 2000, p. 404).

I read *Crossing Over* early in my candidature and found it impressive in terms of its scope and the quality of its execution, and useful in that it pointed me to

important references in the narrative inquiry literature. However, while the book is certainly accessible to a general readership, the authors are medical and nursing academics and the targeted audience, as listed on the back cover, is ‘practitioners and trainees in medicine, nursing, gerontology, ministry, counseling psychology, allied health, and social work’ rather than family caregivers. Also, crucially for my project, the care described took place within homes, hospitals and hospices located in the United States and Canada, countries which have very different health care systems to Australia.

Auto/biographical accounts written by carers that describe the illness trajectory of a particular person may touch upon the difficulties and challenges of caregiving, but often the spotlight is directed toward exploring the life and death of the patient and the relationship between this person and the writer. A beautifully evocative example of this kind is Susan Addison’s memoir about the death of her teenage son, Charlie, *Mother Lode: Stories of home life and home death* (Addison 2001). Using passionate and poetic language, Addison’s stories encompass the world of the family as well as Charlie’s life and death within it:

When all’s said and done, he left us. Charlie left us, his family and friends; we didn’t lose him. How could we? Day and night, we were vigilant. At times I felt that our solicitude, our tenderness, our love was holding him with us; that our hands cradling his were pinning him to his sick bed. The bonds of love were pinning him to a half-life, I feared. This half-life he lingered in was no life for a young man. I knew that. And yet... and yet... life without him was unimaginable. You see, we’d grown into our roles in this drama. We’d thoroughly learned our parts after a month of caring for him at home. Then, mere supporting actors, we had to step in and speak the central actor’s lines when Charlie lost the power of speech (Addison 2001, p. 85)

Another moving portrayal of kinship and caring at the end of life is *Gramp*, which records in words and pictures the mental and physical deterioration of Mark and Dan Jury’s grandfather Frank (Jury & Jury 1978). The sparsely written text records the stigma of senile dementia forty years ago in a small American town and the family’s acceptance of Frank’s decision to stop eating. Haunting photographs on the back cover show Frank holding his grandson as a baby in 1954, and a long-haired Dan holding the wizened, nappied figure of his dying grandfather twenty years later, in 1974.

In a different league entirely is David Rieff’s *Swimming in a Sea of Death: A son’s memoir* (2008), in which he describes feeling obliged to act as Susan Sontag’s chief cheerleader as she struggled ferociously to avoid dying of cancer.

Sontag insisted on one gruelling treatment after another and never, ever accepted that it was possible she might not survive. The *New York Times* reviewer, Abigail Zuger, called the memoir a case book example of a ‘bad death’, one of those ‘miserably protracted and painful affairs that overwhelm everyone – the deceased and survivors alike – with panic, guilt and bitter regrets’ (Zuger 2008). In a similar vein (although with a happier conclusion) *The Spare Room* by Helen Garner (2008) also explores how unrelenting hopefulness in the patient impacts the carer. I mention her novel even though it is billed as fiction, as it provides a searingly honest portrait of a caregiver’s thoughts and reactions and Garner, one of the leading practitioners of creative nonfiction in this country, has admitted it was heavily based on lived experience. In an interview for Radio National’s *The Book Show*, Garner said situations where she had cared for dying people had ‘plumbed the depths of me in ways that turned up some very ugly stuff’ (Koval 2009). She called the narrator of *The Spare Room* Helen because she wanted to own the dark feelings of anger, irritability and compassion fatigue portrayed in the novel.

Virginia Lloyd’s memoir, *The Young Widow’s Book of Home Improvement: A true story of love and renovation* (2008), is primarily about love, loss and grief but also depicts the author’s conflicted response to her husband’s deterioration and increased dependence. She marries John knowing he has advanced cancer, but she has not really accepted the implications of this, and baulks every time his illness encroaches a step further onto the normality of their life together. The poignant section describing the transformation of their sleeping arrangements, seven months into the marriage, begins as follows:

A height-adjustable hospital bed. At first I didn’t understand what the nurses meant. For a moment I pictured our queen-sized mattress atop some contraption that the palliative care nurses raised and lowered at their will and command. Then I understood what they really wanted: to replace the bed John and I shared as husband and wife with a slimline chrome bed with levers and angles and removable rails. They wanted to transform our bedroom into a domestic version of a hospital room, with this clinical bed front and centre (Lloyd 2008, p. 176).

An auto/biographical publication that places the caregiving aspect of terminal illness centre stage is the booklet *A Journey Lived: A collection of personal stories from carers* (Palliative Care Australia, 2005). Thirty-three pages long in total, the booklet contains eight brief, testimonial-style accounts of

supporting a loved one from diagnosis to death. They are plainly and simply written in first-person by the carers, who obviously have been asked to focus on how various palliative care services helped the families to cope. A foreword from the President of Palliative Care Australia explains that the booklet is intended to honour the contribution made by family carers and to highlight the availability of palliative care support services.

The book that comes closest to my 'Hospital Bed at Home' manuscript in terms of presenting true-life accounts of carers' experiences is Megan Hender's *Saying Goodbye: Stories of caring for the dying* (2004), which portrays the experiences of ten carers, including the author. Hender asserts the value of 'a slow death, a more conscious death' for both the dying person and those who love them, and describes the 'difficult but powerful experience' of spending three weeks at the hospital bedside of her mother, who was allowed to die after suffering stroke-induced brain damage. Subsequently, Hender began 'collecting the stories of other people who had "accompanied" a dying person', interviewing them about 'how they managed, both practically and emotionally...the gruelling bits and the good bits...what made it hard and what gave comfort...the involvement of others...grief and recovery...[and] the role of ritual and religion' (Hender 2004, pp. x-xi). Three of the ten stories involve someone dying at home; the others died in hospitals or nursing homes.

Prefaced by half a page of contextual and descriptive information from Hender, each interviewee's story takes the form of a ghosted memoir or "collaborative autobiography"¹, whereby Hender as the author adopts the identity of her informant and writes as "I". Reading this book just before I began work on my manuscript, I noticed that although Hender's use of first person provided a sense of intimacy, it allowed no space for the incorporation of other perspectives. I also noted that some of the stories contained superficial and inconsistent elements, as though she had, as ghostwriter, uncritically accepted the accounts without much probing. Therefore, I decided to opt for third-person narration in all my stories, except of course my own, both as a point of distinction from Hender and, more importantly, as a means of enhancing

¹ The pioneering analysis of this form is Philippe Lejeune's essay 'The autobiography of those who do not write' (1989).

complexity by including information from other sources – the academic literature, other family members, and my own experience. Third-person narration also meant that rather than presenting each story as a stand-alone entity, as Hender had done, I could use myself and my own quest for understanding as the connecting thread between them.

Motivation for exploring this topic

Apart from a few simple, patient-focused brochures, I read no palliative care literature while I was actively engaged in caring for my mother, and did not even know of its existence. Given that I was working as a casual academic and had just finished a Masters degree, it seems odd to me now that I never thought to look for resources to help me understand what I was going through. At the time, my information-gathering was wholly cancer-oriented: my Internet searches were about symptoms, prognoses, treatments, side-effects – never about the person standing on the sidelines watching the disease ravage a loved one.

As I explain in the prologue to ‘A Hospital Bed at Home’, I was unprepared for the overwhelming physical, emotional and psychological challenges involved in home-based palliative care. Being an intelligent, well-organised kind of person, I naively assumed that I would rise to the occasion, but instead found that I was sinking under the stresses, ground down by worry, injury, lack of sleep and anticipatory grief. Recording what I was going through, often in the middle of the night, was part of how I processed this difficult time. But rambling diary entries and early attempts at crafting them into memoir were not enough to allow me to make sense of what I had experienced. Even after my mother had died, I was haunted by her suffering and found myself wishing I could have been a more loving, empathetic, generous-spirited daughter than I had proved to be. I regretted that I had been overly task-focused in my care of her, I puzzled over the chasm between her attitudes towards life, hope and death and my own, and I felt guilt and sorrow about lost opportunities for meaningful, authentic communication. I felt that I needed to find out how other people managed the role of caregiver, and to write about what it had been like for them, in order to set my own experiences into some kind of context. In doing so, I was implicitly aware that in each case, the trajectory of the disease and the mundane

tasks of caregiving would provide the situation, but the story itself would be the deeper truths these people would be sharing with me. As Vivian Gornick explains:

The situation is the context or circumstance, sometimes the plot; the story is the *emotional experience* that preoccupies the writer: the insight, the wisdom, the thing one has come to say (Gornick 2002, p. 13).

The driving engine of my creative writing project can be quite simply expressed as the following question: How do people cope with the challenge of caring for someone who is dying at home? Or, more specifically – how did these particular carers respond to the illness and impending death of their particular loved one, what did they bring to the role of caregiver, what got them through it, and how did the experience impact on or reflect the relationship between themselves and their patient? And, to be honest, somewhere underneath those questions was this one: compared to other people in similar situations, how did I measure up?

A confluence of disciplines

As memoir was my starting point and creative nonfiction was my intended output, I knew my research project belonged in the discipline of creative writing. However, it seemed to me that the project potentially overlapped various other fields as well: most notably health studies, life writing and narrative inquiry. To secure a broad mix of input and advice, I arranged a co-supervisor from the School of Health (with expertise in palliative care and qualitative research) to work with my primary supervisor from the School of English, Communication and Theatre (who had expertise in creative nonfiction and creative arts research higher degrees).

Having outlined the relevant palliative care literature earlier in this chapter, I will now consider how my project relates to the fields of life writing and narrative inquiry. Life writing is an umbrella term extending beyond autobiography, biography and memoir to embrace stories of lived experience across multiple fields, including history, anthropology, psychology, medicine, literary studies and journalism (Eakin 2004). My project incorporates both memoir and the biographical form of life writing where one person (the writer)

produces an account of the life experience of another person (the subject) and the second person cooperates by being interviewed or providing access to documents. To narrow the focus further, my biographical accounts are of a type where the identities of writer and subject remain distinct, not the type where they are artificially collapsed into one by means of first person narration, as in the ghostwritten form of “collaborative autobiography” considered by Philippe Lejeune (1989), Paul John Eakin (1999) and G. Thomas Couser (2001), and utilised by Hender (2004) in her stories of caring for the dying. They are also not “collective biography” (prosopography), as I was more interested in presenting individual experience than I was in analysing the common socio-historical context within which the experiences were situated.

My creative work can legitimately be called “biographical creative nonfiction” because biography, in the rejuvenated form described by Ian Donaldson (2006), can concern itself with just a slice of a life (*1599: A Year in the Life of William Shakespeare*), and can as validly focus on a city (*London: A Biography*), a spicy dish (*Curry: A Biography*), or an ordinary person (*Stuart: A Life Backwards*) as a celebrity. However, a more sophisticated conception of the project – as a biographical type of life writing within the field of narrative inquiry, with an investigation of lived experience culminating in creative nonfiction stories as a research outcome – provides a more substantial and useful base for describing the ethical and methodological research issues that shaped my project’s conduct.

But first, I must unpack my “sophisticated conception” by defining its key terms: creative nonfiction and narrative inquiry.

Creative Nonfiction

Creative nonfiction, also known as the Fourth Genre (with the others being fiction, poetry and drama), literary journalism, narrative nonfiction, New Journalism and literary nonfiction, is a protean form with neither a satisfactory name nor a widely accepted definition (Joseph 2008; Roorbach 2001). Simply speaking, it is a hybrid of literature and nonfiction (Drucker n.d.); it is artful nonfiction (Gomes 2009); it is the use of literary craft to present factually accurate prose in a vivid, compelling manner (Gutkind 2006). Lee Gutkind, who

coined the term in the 1970s, acknowledges that it ‘sounds a bit affected and presumptuous’ (Gutkind 2006); others have complained that it is oxymoronic, with “creative” suggesting the realm of fabrication and “nonfiction” pulling in the opposite direction, toward verifiable fact (Gomes 2009; Ricketson 2006). Bill Roorbach calls it ‘a troublesome term’, but says we seem to be stuck with it, as none of the other contenders are ‘any more accurate or inclusive than “creative nonfiction”, and some are less accurate, and too exclusive’ (Roorbach 2001, pp. 2-3).

By default, then, creative nonfiction has become the accepted way of describing artistic writing based on actual events and real people: true stories engagingly rendered via scenes, dialogue, evocative description, characterisation, thematic development, and the personal voice (Blair 2006; Gutkind 1997). But of course although the label may be relatively new, the practice of applying storytelling techniques to real life has a lineage stretching from Chloe Hooper, Helen Garner, Tom Wolfe, Truman Capote, George Orwell, Ernest Hemingway and Charles Dickens (just to name a few) back as far as Michel de Montaigne’s personal essays and perhaps even Homer’s *Iliad*, famously deployed as a nonfiction document by an archaeologist to locate the actual remains of Troy (Forché & Gerard 2001; Gerard 1996).

Donna Lee Brien notes that the term is broad enough to encompass writing ‘as diverse as memoir, fictionalised biography, autobiography and other lifewriting, some literary/New Journalism, the “creative” essay, innovative self-aware critical fiction, and various forms of experimental and narrative/dramatised history writing’ (2000). Given the elephantine ambit of creative nonfiction, it is not surprising that proponents viewing it from various standpoints tend to emphasise different features when defining it. Michael Steinberg locates the heart of creative nonfiction in the region of personal essay and memoir, claiming ‘the fourth genre’s identity is more connected to the spirit of Montaigne’s work than it is to matters of subject, reportage and/or scholarly research’, a focus which gives primacy to ‘the writer’s thoughts, feelings and reflections’ (1998, p. vi). This stands in contrast to Gutkind’s definition of the “mission” of the genre, ‘which is to gather and present information, to teach readers about a person, place, idea or situation’ (1997, p. 70); not to mention his warning that an excess of subjectivity is one of the main reasons for rejection of

submissions to his literary journal, *Creative Nonfiction*. Gutkind counsels against ‘an overbearing egocentrism’ where ‘writers write too much about themselves without seeking a universal focus or umbrella so readers are properly and firmly engaged’ (Gutkind 1997, pp. 69-70).

The key to understanding how such seemingly divergent definitions have arisen, suggests Bill Roorbach, is to recognise that creative nonfiction divides into three main sub-genres: literary memoir (true life stories based primarily on memory); the personal essay (the reflective exploration of ideas, places, events, situations); and literary journalism (storytelling, character development and other artful techniques in the service of news and information). However, Roorbach argues, although memoirists, essayists and journalists may look askance at each other and valorise different features of the creative nonfiction genre, their work can be accommodated on the same literature shelf by virtue of having particular values in common and aspiring to be art (Roorbach 2001). In brief, the values or attributes he identifies are: language deployed with talent and skill; a discernable and subjective self at the centre of the work either explicitly as “I” or implicitly via the writerly voice; accuracy, which does not necessarily mean a deadening insistence on “verifiable facts”; a sense of urgency about the importance of the subject; the provision of surprising ideas or insights; a complex, multi-layered handling of the issues; and ambitious execution driven by intelligence (Roorbach 2001).

Philip Gerard posits a slightly different, and I believe more astute, set of defining characteristics. After emphasising that the “nonfiction” part of the name implies an inescapable ‘allegiance to the truth of events’ (1996, p. 5), he answers the question of what makes some nonfiction “creative” by listing five hallmarks. Firstly, that creative nonfiction has both an “apparent” and a “deeper” subject (1996, p. 7). The apparent subject – such as a famine, or a sailing trip – may be big and newsworthy or small and quirky, but it must be grounded in particulars and rendered fascinating. The deeper subject – such as how to deal with global poverty, or a meditation on the creative process – gives the piece an enduring meaning, a timelessness, and that timeless quality is Gerard’s second characteristic. The third is narrative – ‘creative nonfiction always tells a good story’ (1996, p. 9) – with action, scenes, character, plot and dialogue used to craft a compelling account. Fourth, creative nonfiction is imbued with ‘a sense of

reflection on the part of the author'; that is, it contains not just research but also rumination, connections and sophisticated insights. And finally, nonfiction that counts as creative 'shows serious attention to the craft of writing' (1996, p. 10) – it is elegant and graceful and falls rhythmically on the ear. The writing sings.

Amalgamating elements of the two lists to form one succinct set provides me with a working definition of creative nonfiction. It is about real people and real events; has both an apparent and a deeper, timeless subject; has a discernable, ruminative self at the centre of the work; is accurate, insightful, surprising and complex; tells a good story; and has writing that sings.

Narrative Inquiry

Narratives of lived experience, with their rich and engaging details of character, circumstance, intention, beliefs and connections between events, have long been an appealing way to make sense of complex phenomenon (Barnard et al. 2000; Polkinghorne 1988). As Michael Novak says:

Story...is an ancient and altogether human method. The human being alone among the creatures on the earth is a storytelling animal: sees the present rising out of a past, heading into a future; perceives reality in narrative form (Novak 1975, p. 175).

Narrative inquiry is a subset of qualitative research that uses narratives to describe and understand human action (Polkinghorne 1995). According to *The SAGE Dictionary of Qualitative Inquiry*, it encompasses 'the interdisciplinary study of the activities involved in generating and analysing stories of life experiences (e.g. life histories, narrative interviews, journals, diaries, memoirs, autobiographies, and biographies) and reporting that kind of research' (Schwandt 2007, p. 203). Jean Clandinin and Michael Connelly put it more simply: 'Narrative inquiry is stories lived and told' (2000, p. 20). Catherine Kohler Riessman notes that the term "narrative", often used synonymously with "story", lacks a clear-cut definition. It can refer to 'an entire life story, woven from threads of interviews, observations and documents' as well as 'a discrete unit of discourse: an answer to a single question, topically centered and temporally organised' (2007, p. 429). She identifies the essential ingredients distinguishing narrative from other forms of discourse (for example, chronicles, reports, arguments) as sequence and consequence. 'Events are selected, organised,

connected, and evaluated as meaningful for a particular audience' (Riessman & Speedy 2007, p. 430). Donald Polkinghorne divides narrative inquiry into two camps: one that collects people's storied accounts of their experiences and uses this as data to be analysed for the purpose of exploring themes, developing categorisations, or interpreting constructs like self-identity, social roles or cultural norms; another that gathers descriptions of events and actions, and configures them into an emplotted story unfolding over a certain period of time (1995). The latter type of narrative inquiry is the one I have employed in my project.

Narrative research has become increasingly common in such academic disciplines as history, anthropology, psychology, sociology, linguistics, education and health studies (Riessman & Speedy 2007). The "narrative turn" in academia began in the 1970s, concurrent with the advent of New Journalism's shift toward literary language, storytelling forms and an explicit point of view: both arising from dissatisfaction with the prevailing normative ideal of presenting social reality from a detached, neutral, authoritative, pseudo-objective standpoint (Barone 2008).

The acceptance of narrative in social science research was bolstered by Jerome Bruner's (1986) assertion that storytelling is more than a vehicle for emotional expression: it is a mode of cognitive functioning. Bruner describes the narrative mode as a legitimate form of knowing that is complementary to, but not reducible to, the logico-scientific mode, arguing that it offers a distinctive way of ordering experience and constructing reality. Instead of looking for general causes and universal truths, the narrative mode is context-sensitive and particular, it 'deals in human or human-like intention and action and the vicissitudes and consequences that mark their course' (Bruner 1986, p. 13). As well as recounting action occurring at a specific time and place, stories offer insight into consciousness and meaning, telling us what the people involved in the action 'know, think or feel, or do not know, think or feel' (Bruner 1986, p. 14). Bruner's analysis in *Actual Minds, Possible Worlds* (1986) focuses on literary fiction, but contains the seed of an idea that has since become commonplace: that people account for their experiences in terms of narrative structures; that we lead storied lives. Furthermore, in telling stories, people

evaluate the events they describe, justifying or condemning their own and others' actions, and presenting themselves as choice-making agents:

How, indeed, could a subject of action give an ethical character to his or her own life taken as a whole if this life were not gathered together in some way, and how could this occur if not, precisely, in the form of a narrative?' (Ricoeur 1992, p. 158).

In depicting behaviour as meaningful, stories fall between description and prescription (Ricoeur 1992). They invite us to see the point of people's actions, and to consider the ethical dimensions of their attitudes, feelings and behaviours in terms of social practices and shared traditions (Widdershoven & Smits 1996). Thus, stories have moral significance: they can be 'evaluated as answers to the question of how to live' (Widdershoven & Smits 1996, p. 281).

Qualitative research and the realm of stories have a natural affinity. Anthropologist Harry Wolcott advises: 'Qualitative researchers need to be storytellers. That, rather than any disdain for number crunching, ought to be one of their distinguishing attributes' (1994, p. 17). However, not all qualitative research reports make riveting reading. Laurel Richardson confesses to having 'yawned my way through numerous supposedly exemplary qualitative studies' for thirty years. She bemoans the mechanistic "writing-up" model that 'ignores the role of writing as a dynamic, creative process' and says it has created a 'flotilla of qualitative writing that is simply not interesting to read because adherence to the model requires writers to silence their own voices and to view themselves as contaminants' (Richardson 2000, pp. 924-5). She praises the diverse new forms of research-based creative analytic practices that acknowledge a situated subjectivity engaged in knowing and telling, particularly those representations 'that deploy literary devices to re-create lived experience and evoke emotional responses' (Richardson 2000, p. 931). These include autoethnography (revealing, first-person texts where the writer interrogates their own lived experience and relates the personal to the wider cultural context); performance texts (research presented in spoken, sung, danced, filmed or theatrical forms); ethnographic fiction (stories that draw on both imagination and fieldwork); and, of course, creative nonfiction. Richardson says that these kinds of evocative representations allow researchers to relate differently to their

material, as it ‘touches us where we live, in our bodies’ and encourages attention to feelings, doubts and uncertainties (2000, p. 931).

Narrative inquiry rendered as creative nonfiction allows the researcher to engage in open and transparent self-reflexivity about the process involved in producing the text and to acknowledge his or her own preconceptions and point of view. As Brien notes, creative nonfiction:

is particularly suited to a focus on the personal, on human values and ethical issues, on a sense of the self in action, and on material which deals with emotional content in a way that texts which aim to be totally objective may not be able to. Creative nonfiction is thus the perfect vehicle for the writer who wishes to reveal the impossibility of any immaculate objectivity when it comes to writing nonfiction, and instead wants/needs to revel in a subjective approach (Brien 2000).

Stefinee Pinnegar and J. Gary Daynes identify “blurred knowing” as a fundamental element of the turn to narrative within the academy. By this they mean that narrative inquirers accept that there are multiple ways of understanding human experience, and value the existence of ‘wondering, tentativeness, and alternative views’ within the research account (Pinnegar & Daynes 2007, p. 25). Like literary texts, a well done narrative study offers its readers not generalisable knowledge claims, but rather an expanded sense of the topic and its complexities, as well as the opportunity for ‘vicarious testing of life possibilities’ (Clandinin & Connelly 2000, p. 42). In ‘Creative nonfiction and social research’, Tom Barone discusses how creativity in the presentation of social research can entice readers into the internal world of the text and allow them to connect and empathise with the situation and the characters as they would in reading fiction. The subtlety and complexity that a literary presentation can introduce promotes ambiguity rather than certainty, and provides space for a reader to derive meaning that is personally relevant, ‘to take the text home into the world of her daily experiences to see what it might say about familiar conditions, conventional practices, and the values and ideologies that support them’ (Barone 2008, p. 112).

The problem of interpretive authority

Although narratives of lived experience may serve to convey significant truths about the human condition, ever since postcolonialism turned its critical gaze on

anthropology, and the subjects of ethnographies began to “speak back” about misrepresentation and misappropriation of their lives and cultures, there has been much concern about the ethical aspects of life writing among academic practitioners, theorists and critics. As Clifford Geertz notes, ‘What had once seemed only technically difficult, getting “their” lives into “our” works, has turned, morally, politically, even epistemologically delicate’ (1988, p. 130). In the final chapter of *How Our Lives Become Stories: Making selves*, Eakin points out that life writing depends on a “fiction”, namely that individuals and their lives can be commodified in the form of a textual representation; this fiction then creates the possibility of disrespecting a person by treating them as a “thing” to be pinned down and evaluated, thereby assaulting their very personhood (1999, p. 172). The acts of biographical transgression he discusses include Kathryn Harrison’s scandal-provoking book, *The Kiss* (1997), detailing the incestuous relationship she had with her father when she was in her early twenties; the blistering attacks launched on Ted Hughes by those who wrote the life of Sylvia Plath after her suicide; and the inadvertent betrayals committed by John Neihardt in authoring *Black Elk Speaks* (1932), which purported to relate the story of a Sioux Indian medicine man. Eakin then goes on to measure tell-all memoirs, adversarial biographies and collaborative autobiographies against a traditional ethics of privacy, and comes close to suggesting that, as even well-meaning ethnographers and literary biographers appear to be ‘engaged in exploiting other people’s lives for their own purposes and profits’, it may be advisable to abandon writing about other people altogether (Eakin 1999, p. 175).²

Critic G. Thomas Couser, who applies the moral scruples of biomedical ethics to writing that depicts the lives of those rendered vulnerable by age, or physical or mental impairment, warns that the risk of betrayal is highest in consensual, cooperative biographical work: ‘The closer the relationship between writer and subject, and the greater the vulnerability or dependency of the subject, the higher the ethical stakes’ (Couser 2004, p. xii). In *Vulnerable Subjects: Ethics and life writing* (2004), Couser analyses various ethically problematic situations: parents writing about disabled children; case studies of patients with

² Having spent the rest of the book arguing that identity, and therefore privacy, should be considered in relational terms, he is able to pull back from the brink.

quirky afflictions by neurologist Oliver Sacks, author of *The Man Who Mistook His Wife for a Hat* (1987);³ and narratives justifying acts of euthanasia written by those who acquiesced or assisted. Couser wishes to draw attention to vulnerable subjects who are ‘customarily on the receiving end of life writing... who get represented by others’, while bearing in mind that any deliberation on the ethics of life writing ‘entails weighing competing values’: the desire to tell one’s story versus the need to protect others, the obligation to truth and the obligations of trust, the individual’s right to privacy as opposed to the wider benefits of disclosure (Couser 2004, p. 198).

Similarly, when a creative nonfiction story is crafted from someone else’s lived experience, striking an appropriate balance between the interpretive authority of the writer and the ethical treatment of the informant can be a complex, angst-ridden undertaking. Narrative researchers and creative nonfiction writers may, like journalists, find themselves assailed by conflicting loyalties – to their interviewees, to their readers, to their own sense of what the story is about. This quandary is presented with coruscating hyperbole by Janet Malcolm:

Every journalist who is not too stupid or too full of himself to notice what is going on knows that what he does is morally indefensible...The catastrophe suffered by the subject is no simple matter of an unflattering likeness or a misrepresentation of his views; what pains him, what rankles and sometimes drives him to extremes of vengefulness, is the deception that has been practiced on him. On reading the article or the book in question, he has to face the fact that the journalist – who seemed so friendly, so sympathetic, so keen to understand him fully, so remarkably attuned to his vision of things – never had the slightest intention of collaborating with him on his story but always intended to write a story of his own. The disparity between what seems to be the intention of an interview as it is taking place and what it actually turns out to have been in aid of always comes as a shock to the subject (2004, p. 3).

As Ian Jack points out in his introduction to *The Journalist and the Murderer*, Malcolm’s famous opening sentence may be an over-generalisation, but the same charge could be levelled at *Pride and Prejudice* – ‘Universally, Miss Austen, even among pederasts with good fortunes, or among the heathen races?’ (Malcolm 2004, p. x). Regardless of its attention-grabbing rhetorical flourishes, Malcolm’s text highlights profound and troubling issues of manipulation and betrayal in the journalistic-style interview-based encounter, particularly those in

³ Disabled British academic Tom Shakespeare has described Oliver Sacks as ‘the man who mistook his patients for a literary career’ (cited in Couser 2004, p. 83).

the service of what Jack refers to as ‘more artful, more ambitious’ forms of journalism, such as literary reportage, long profiles and book-length works which require the establishment of a relationship of trust between interviewer and interviewee. It also raises the question of how to proceed in a manner that is not ‘morally indefensible’ when subjects’ rights come into conflict with authors’ rights. As Matthew Ricketson notes, such journalists ask those they write about

to trust them with their innermost thoughts and feelings, and then grant them full independence to write as they see fit. That is trust of a high order. It is tempting for the writer to promise anything to gain the precious access, and then ignore the subject’s plaintive cries once they have got what they want (Ricketson 2006).

In the context of academia, life writing has been characterised as ‘the field of Creative Arts study and practice that currently offers most difficulty for the marriage of ethics procedures and creative endeavour’ (Evans 2005). It is tempting to think that when research based on lived experience is done under the aegis of a university, with scrutiny of the protocol by a Human Research Ethics Committee (HREC), participants can be assured of appropriate levels of respect and protection. However, the guidelines that HRECs enforce have their origins in health and medical research and are oriented towards quantitative scientific methods like experiments and surveys (Richards & Schwartz 2002). The revised *Australian National Statement on Ethical Conduct in Research Involving Humans* (National Health and Medical Research Council 2007) was notable in that it included, for the first time, some discussion of qualitative research; but the guidelines provided are far from comprehensive and leave much to the discretion of the individual, despite the fact that, as David Bakan points out:

The most significant truths about human beings inhere in the stories of their lives. Yet they need protection for making their stories available to others (Bakan 1996, p. 5).

Some narrative research has description as its ultimate aim, and seeks to confine itself to a faithful rendition of participants’ life experiences from an *emic*, or insider, point of view. In such cases, the researcher ‘conceives the role as being a collaborator and a conduit rather than an interpreter’ and may encourage participants to be involved in fashioning the final text (Josselson 2007, p. 548). More commonly, however, researchers take accounts of lived experience, filter them through a theoretical framework, and use them to shed

light on general cultural processes or phenomena (Chase 1996; Richards & Schwartz 2002). The written-up research product is usually oriented to an academic audience and may incorporate an analysis of participants' attitudes or actions that is not entirely flattering. This can leave the researcher feeling discomfited by the prospect of it being read by the original source. Ruthellen Josselson describes the dread of being confronted with 'How could you say that about me?' and the ambivalence she feels in switching her allegiance from participant to reader:

Where in the interview I had been responsive to them, now I am using their lives in the service of something else, for my own purposes, to show something to others. I am guilty about being an intruder and then, to some extent, a betrayer' (Josselson 1996a, pp. 69-70).

Participants may be shocked to find that what they have told the researcher has been interpreted in a way that is alien to their own conceptions about their identity and the meaning they attach to their experiences. They may also feel angry and exploited:

No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own (hooks 1990, p. 343).

A thought-provoking example of this situation can be found in Katherine Borland's article "'That's not what I said": Interpretive conflict in oral narrative research' (2006), in which she reveals how unimpressed her grandmother was to find her anecdote about a day at the races had been recast as an illustration of female struggle for autonomy within patriarchal structures. However, in her analysis of this incident, Borland does not advocate what she calls the 'unsatisfactory if not illusory solution' of refraining from interpretation and simply 'letting the subjects speak for themselves' (2006, p. 311), as she believes that part of her scholarly role is to create more textured meanings. Instead, she suggests that talking with participants about interpretation can avoid the assumption of commonality where difference exists:

I am suggesting that we might open up the exchange of ideas so that we do not simply gather data on others to fit our own paradigms once we are safely ensconced in our university libraries ready to do interpretation. By extending the conversation we initiate while collecting oral narratives to the later stage of interpretation, we might more sensitively negotiate issues of interpretive authority in our research (Borland 2006, p. 319).

Even a researcher attracted to the feminist ideal of collaborative research methods might decide to exercise unilateral control over the interpretive process. In writing her book, *Ambiguous Empowerment: The work narratives of women school superintendents* (1996), Susan Chase decided for pragmatic reasons not to share her interpretations with participants prior to publication. She felt that she was ‘racing against the tenure clock’ and could not afford time for consultation and negotiation, nor could she afford the risk of losing an entire chapter if one of the four women whose narratives she had extensively analysed withdrew her contribution. She notes:

I felt I had adequately fulfilled my ethical responsibility to participants by sending them their interview transcripts and asking for permission to use specific passages. I had already done more than most social scientists who usually stop at obtaining signatures on informed consent forms (Chase 1996, p. 49).

Revisiting the decision later, Chase argues that her analysis of the discursive, narrative and linguistic processes embedded in the stories would not have been clarified or validated by participant feedback. She recognises the divergence between her communicative agenda and what the women themselves wanted to express in talking about their experiences, but hopes that her research served their interests ‘in a deeper sense’ by illuminating how stories of accomplishment and discrimination act to preserve or disrupt individualistic, gender- and race-neutral assumptions in discussions about professional work. In her concluding thoughts, Chase suggests that informed consent forms be tailored to the processes of specific narrative projects and carry an open acknowledgement that even if participants are offered some form of ongoing negotiation over the use of their stories, ‘in the end, we claim authority over the interpretive process’ (Chase 1996, p. 57).

In contrast to the angst about appropriating lives voiced by narrative researchers, biographers tend to wear their interpretive independence as a badge of honour. Janet Malcolm (1995) famously likens them to burglars: peeping through keyholes, rifling through drawers, triumphantly bearing away their loot of dark family secrets and never-before-told anecdotes. In the situation where the subject or family propose to cooperate with the enterprise of turning their life into a narrative, the metaphor she employs is that of the Great White Hunter. The friendly tribe trade their memories for a memorialising account, but they must

not assume that their view of what it all means will prevail. Like an explorer appropriating the territory by exercising naming rights, the biographer stakes his or her claim to the dominant authorial voice. To behave otherwise is to run the risk of being unduly influenced by the natives and ending up with a worthless hagiography. However, some biographers become so disenchanting by the nature of their work that they give it up altogether; Cassandra Pybus being one such example (Lindemann 2007). In her article, 'Dogs in the graveyard' (2000), Pybus describes the 'disconcerting and disagreeable dilemma' of believing writers have an ethical responsibility to consider how their work may expose or hurt living people whilst also feeling ethically bound to write what she sees as an honest and complete account:

my writerly integrity is bound up in the veracity of the tale I am able to construct out of the vagaries of memory and the treacherous detritus left behind. Since we can never know the truth, it is fundamentally important that what I write makes psychological and moral sense of the material available to me and that my story does say something meaningful about the human condition (Pybus 2000).

Like biographers, creative nonfiction writers prize their interpretive independence and take a strong stance on the issue of writerly integrity. Although creative nonfiction is billed as "the literature of reality" and seeks to be scrupulously accurate in its presentation of information, detached objectivity and impartial coverage of opposing views are not part of its mission. One of the characteristics distinguishing creative nonfiction from conventional journalism is that writing subjectively is 'not only permitted but encouraged' (Gutkind 1997, p. 15). Creative nonfiction is animated by a personal voice; explicitly or implicitly there is always an "I", a lively intelligence behind the words, making sense of the subject (Perl & Schwartz 2006). In 'Living to tell the tale: The complicated ethics of creative nonfiction', Lynn Bloom writes approvingly of the 'implacable I' and declares that 'writers of creative nonfiction live – and die – by a single ethical standard, to render faithfully, as Joan Didion says in "On Keeping a Notebook", *how it felt to me*, their understanding of both the literal and the larger Truth' (Bloom 2003, p. 278).

Given this valorisation of a personal point of view in creative nonfiction, it is probably not very surprising that when ethics are discussed, the rights of the author in the artistic expression of his or her account, and the rights of the reader

in reception of it, receive more vociferous proclamation than subject's rights. As Steve Evans (2005) attests, ethics chapters in creative nonfiction textbooks tend to dwell on issues such as 'faithfulness to truth and the rights of the reader not to be fooled' rather than addressing the proper treatment of human research subjects. Relative allocation of space provides a crude but significant indication of perceived importance. As an example, in discussing implicit covenants about accuracy and candour Mark Kramer devotes two pages to 'The Writer's Relationship to Readers', compared to one page for 'The Writer's Relationship to Sources' (1995, pp. 23-6). Lynn Bloom notes that much of the advice about how to write ethical creative nonfiction is couched in legal rather than moral terms: the focus is on 'prudence and jurisprudence', or how to avoid being sued by the people you write about (2003, p. 278).

The ethical quandaries of life story research, which arise from the risk that the textual representation may threaten the subject's privacy, reputation or sense of self (Couser 2004; Eakin 1999), cannot be simply addressed by means of the standard Human Research Ethics Committee measures related to informed consent, confidentiality and anonymity. Firstly, providing a clear explanation of the nature of the study and estimating the risks to participants is often difficult in such cases, as the research focus is more likely to be emergent than predetermined. In this situation, locating informed consent before data collection begins, and requesting upfront agreement to publications based on that data, is an ethically problematical practice (Richards & Schwartz 2002), given that the participants 'can, at the outset, have only the vaguest idea of what they might be consenting to' (Josselson 1996b, p. xii). Also, the protection of personal information via anonymity is almost impossible to guarantee when the material being gathered is richly descriptive and the aim is to present it in its proper context rather than stripping it of all identifying features. The inescapable conclusion is that there are no easy solutions: 'Merely waving flags about confidentiality and anonymity is a superficial, unthoughtful response' (Josselson 1996b, p. xii). As a way forward, some narrative researchers (for example Clandinin & Connelly 2000; Ellis 2007; Josselson 2007) advocate a form of ethical thinking which takes account of specific situations and the responsibilities embedded in particular relationships (relational ethics), rather than relying on general rules and procedures to provide answers. Relational ethics promotes the

values of care, trust, empathy and dialogue in human relationships, and is linked to feminist philosophies that have developed in opposition to Kantian conceptions of universal moral principles and rational, autonomous individuals (Christians 2000; Koehn 1998). Relational ethics emphasises connectedness and ‘requires researchers to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and to initiate and maintain conversations’ (Ellis 2007, p. 4).

Determining how to deal with the ethical tensions involved in telling a story about someone else’s life in a way that would not hurt, exploit or misrepresent them, while still telling it in a way that would preserve my integrity as the writer of that story, was to become a central aspect of my research project. In his keynote address to the *Eleventh Annual Conference of the Australian Association of Writing Programs*, Brad Haseman noted that practice-led research, involving theses which combine creative work and exegesis, should meet ‘the first test of all research’ – that there is a problem to be investigated. However, unlike more conventional research designs, ‘its definition will emerge during the research and it may well be that it is only in the final stages that a practice-led researcher will articulate and explicitly connect the problem with the trajectory their research has taken’ (Haseman 2007). I first caught sight of my core research problem early in my candidature, initially while I was preparing my ethics application, and again during the process of writing the first story of my creative work. Therefore, it was able to exert a shaping influence on my research design and creative practice. However, in line with Haseman’s suggestion that the trajectory of its effect may be easier to perceive retrospectively, my ideas about the ‘ethical conduct versus writerly integrity’ dilemma became clearer as the project proceeded; as I came to understand that the highly consultative methods I had adopted were enhancing rather than diminishing my stories. With hindsight, I can say that what I sought to do was *to take a non-exploitative, non-maleficent approach to the task of producing non-superficial, non-rose-tinted, nuanced accounts of home-based palliative caregiving*. Full details are contained in Chapter Three, which provides an in-depth account of the conduct of my project.

Chapter Three

CONDUCT OF THE PROJECT

This chapter presents the theoretical framework within which this research project is located and my position on the concept of truth as it relates to life writing. It describes how ethical considerations shaped the research design, and then turns to the conduct of the project: how I recruited participants, gathered materials, and created the stories.

Choosing a theoretical approach

The mindset I brought to my doctoral project was that of a social science researcher schooled in qualitative methods, albeit one who knew she wanted to write up her results in the form of a literary text rather than as an academic report, using storytelling techniques to portray lived experience in a vivid and emotionally engaging manner. My initial proposal stated that the research would fall under the interpretive paradigm and would use written materials and in-depth interviews as data. I mentioned creative nonfiction as the overarching genre, but left open the issue of whether the narrative would be organised as thematic essays interweaving participants' experiences in common areas, or as discrete biographical stories focusing on individual participants.

Early in my candidature, I attended a workshop organised by the Humanities Research Centre at the Australian National University, titled *Using Lives*, which was aimed at postgraduate students whose thesis could be connected in some way to the biographical turn in humanities and social science research. The experience tipped me decisively toward presenting my work as biographical creative nonfiction, but left me wondering how far along the “interpretive” continuum to situate myself. Was I willing to accept that there are no facts, only interpretations, all of equal standing? How would this gel with the creative nonfiction genre, ‘the literature of reality’ (Gutkind 1997), whose exponents urge ‘a fidelity to accuracy, to *truthfulness*’ (Forché & Gerard 2001, p. 1)?

In his important and influential work, *Interpretive Biography*, Norman Denzin (1989) argues that all accounts of a life are fictional and people create themselves in the process of performing their autobiographical stories. There is no real person having real-life experiences to refer to – there is just the text:

Lives and the biographical methods that construct them are literary productions...writers and readers conspire to create the lives they write and read about. Along the way, the produced text is cluttered by traces of the life of the “real” person being written about (Denzin 1989, p. 26).

I was not happy with this position; not willing to subscribe to the view that fact and fiction are indistinguishable and that there is no way of judging the comparative validity of different interpretations. I certainly intended that my fieldwork would produce something more substantial than a text ‘cluttered by traces’ of the real people I would write about. In short, I did not want to take a postmodern theoretical approach that would oblige me to give up the nonfiction aspect of the creative nonfiction genre. I believe that the line separating fact from fiction, even if only ever imperfectly apprehensible, needs to be preserved; and that knowledge claims about the physical and social world, even if only ever held tentatively, must be susceptible to evaluation. A postmodernist approach would have been quite compatible with my focus on intimate personal experience and my storytelling presentation style, but choosing it would have run counter to my own intellectual unease with radical skepticism.

So, I went back to the methodological literature to find a more congenial theoretical framework. I wanted to plot a middle course, rejecting both naïve realism and a noncritical pluralism of “realities”; I wanted something akin to the stance taken by narrative researchers Amia Lieblich, Rivka Tuval-Mashiach and Tamar Zilber:

We do not advocate total relativism that treats all narratives as texts of fiction. On the other hand, we do not take narratives at face value, as complete and accurate representations of reality. We believe that stories are usually constructed around a core of facts or life events, yet allow a wide periphery for freedom of individuality and creativity in selection, addition to, emphasis on, and interpretation of these ‘remembered facts’ (Lieblich, Tuval-Mashiach & Zilber 1998, p. 8).

Broadly speaking, interpretivist qualitative methodologies such as hermeneutics, narrative inquiry, ethnography and phenomenology aim to study people in a way that ‘takes into account the social actor’s reasons and the social context of action’

(Neuman 2000, p. 76), building on Max Weber's concept of *verstehen*, which refers to developing an empathic understanding of another's worldview (Neuman 2000, p. 547). Hermeneutics emphasises a detailed, dialectical reading of a "text" (which can be a conversation or pictures as well as written material), to contemplate the inherent meanings, seek connections amongst the parts, and get inside the viewpoint it presents (Neuman 2000). In order to understand a part of the text under consideration (the specific sentence, utterance, or act), the inquirer must grasp the whole (the complex of intentions, beliefs, and desires or the institutional context, social practice, form of life), and vice versa (Schwandt 2000).

The epistemology, or theory of knowledge, informing interpretivist methodologies is constructionism. Unlike objectivism, which posits that 'truth and meaning reside in their objects...and appropriate methods of inquiry can bring us accurate and certain knowledge' (Crotty 1998, p. 42), constructionism claims that meaningful reality is 'contingent upon human practices, being constructed in and out of interaction between human beings and their world' (Crotty 1998, p. 42). However, unlike subjectivism, which according to Michael Crotty (1998) is the epistemology behind structuralist, post-structuralist and postmodern forms of thought, meaning in constructionism is not arbitrarily imposed on reality:

we do not create meaning. We construct meaning. We have something to work with. What we have to work with is the world and objects in the world...they are our partners in the generation of meaning and need to be taken seriously (Crotty 1998, pp. 43-4).

Of course, meaning-making is not a wholly individualistic enterprise. We inherit historical and cultural systems for making sense of the world; 'we are born into a world of meaning', says Crotty (1998, p.54). The term *social constructionism* recognises this collective generation and transmission of meaning through language and social practice (Crotty 1998; Schwandt 1994). Within the theoretical framework of social constructionism, a life story is not a fiction, it is a context-bound presentation of experience and self-identity which constructs and transmits individual and cultural meanings (Lieblich, Tuval-Mashiach & Zilber 1998).

Therefore, after due consideration, I decided that an interpretive approach underpinned by Crotty's mild form of social constructionism⁴ was a congruent and congenial theoretical framework for my research project, offering a good pragmatic fit with the empirical aspects of the project as well as a good intellectual fit with myself as the researcher.

Producing truthful accounts

As Donald Polkinghorne notes, narrative researchers 'undertake their inquiries to have something to say to their readers about the human condition' (2007, p. 476). Even when the end product is not interpretive analysis but rather a story offering insight into lived experience, which is freely acknowledged to be only one of many possible tellings, the question still arises: how credible or trustworthy is this account? In what follows, I will address this issue from two perspectives: that of the oral historian or narrative researcher trying to gather truthful material, and that of the creative nonfiction writer trying to tell a truthful story.

Those who embark upon the task of interviewing people about life events confront some particularly thorny issues relating to both the capacity and the willingness of the subject to remember and voice their experiences. Truth as retrieved by memory is a slippery customer, warns Inga Clendinnen (2000), as hard to grasp as a writhing, muscular eel. A model of memory as an 'active process of creation of meanings' rather than a 'passive repository of facts' is critical to the modern practice of oral history; it is now widely accepted that memory is 'partial and selective... affected by the subjectivity of the speaker and the audience for the story, and influenced by the passage of time' (Perks & Thomson 2006, p. 211).

However, subjective, meaning-infused recollections of life events are 'the best evidence available to researchers about the realm of people's experiences' (Polkinghorne 2007, p. 479), provided that researchers working with such accounts bear in mind the following issues:

The limits of language – the experience itself may be more intricate than the person being interviewed can articulate;

⁴ It should be noted that constructionism comes in a multitude of guises, from mild to radical. Schwandt (2000) identifies "strong" constructionism as a postmodernist epistemology.

The limits of what is consciously understood – Merleau-Ponty (1990) said it is as if people are shining the light of reflection into a well. The light only carries so far, and the well is deeper than the light can penetrate. This deeper portion remains in the dark and, thus, cannot be observed;

The problem of social desirability bias – the person may have filtered out those parts of their experiences that they want to keep to themselves or that they believe will present a socially undesirable self-portrait;

The contextual and co-created nature of texts – Mishler (1986) describes how an interviewee reads an interviewer's personal presentation, demeanour and body language to discover what responses are acceptable. Texts generated by interviews are not attributable to a single person – they are creations of an interaction between the interviewer and the participant, which has taken place in a certain context (Polkinghorne 2007).

These threats to the validity of oral testimony cannot be eliminated, but they can to some extent be mitigated. Every historical source derived from human perception is subjective, but at least the oral source 'allows us to challenge that subjectivity: to unpick the layers of memory, dig back into its darkneses, hoping to reach the hidden truth' (Thompson 2000, p. 173). Although a person may change in such a way that the valuation and colouring of their account is altered, often

narrators are capable of reconstructing their past attitudes even when they no longer coincide with present ones...If the interview is conducted skilfully and its purposes are clear to the narrators, it is not impossible for them to make a distinction between present and past self, and to objectify the past self as other than the present one (Portelli 2006, p. 37).

Polkinghorne (2007, pp. 480-2) offers a summary of various techniques that can help reduce the disjunction between a person's meaningful experience and the description they give of it. The use of figurative instead of literal language may assist a participant to put a complex feeling into words. More of the experienced meaning may be brought into awareness if the interview process includes opportunities for the participant to reflect upon and perhaps revise their initial account. Hesitation about projecting a self-image that is not entirely positive may be reduced if the participant comes to trust that the interviewer is not judgmental. In the last two situations, this is more likely to occur if multiple interviews take

place over a period of time, rather than having one interview on a single occasion. Finally, as Mishler (1986) cautions, interviewers need to be aware of the ways they may influence a participant's responses, and strive to ensure that the participant's experiences predominate in the co-created text rather than the interviewer's own agenda.

As will be demonstrated in the discussion of how my research was conducted, I did employ many of the techniques recommended above. Participants understood that I wished to recreate what it had been like for them to care for a terminally-ill person at home, and they were encouraged to write and speak about their experiences in a rich and detailed manner. They were interviewed on multiple occasions over the course of several months, and I began writing early in the process, iterating between gathering information, drafting the narrative, and soliciting feedback. Each interview session developed and deepened the draft version of the story, showed the participant what I was doing with the material they had given me, and provided reassurance that it was my intention to understand and respect their perspective.

Creative nonfiction and truthfulness

Unlike conventional nonfiction, which generally seeks to present objective reality from the standpoint of a detached, neutral observer, creative nonfiction derives much of its power from weaving objective facts and subjective interpretation together to reach a truth that resonates on both an intellectual and an emotional level (Gutkind 1997). As Cheney explains:

Both groups of nonfiction writers, traditional and creative, aim for the same thing – truth, the accurate portrayal of life. They differ on what “truth” means and what such accuracy involves: whether a camera lens is a more accurate reporter of people, things, and events, or whether the human eye that sees in an emotional context best observes and conveys the large and small truths of human existence (Cheney 1991, p. 34).

However, in striving to portray both objective and subjective truths in an artistic manner, creative nonfiction writers may walk a fine line between fact and fiction. All writers select what they consider to be the best (most revealing, most interesting, most important) details to tell a story; it is patently obvious that choices must be made because ‘everything can't be said’ (Cheney 1991, p. 48). Creative nonfiction writers also deploy the rhetorical devices commonly

associated with fiction – dramatic scenes, characterisation, dialogue, richly descriptive and emotive language – to make the writing lively and engaging, to enhance its persuasive power, and to project their own unique style, or voice (Cheney 2001; Perl & Schwartz 2006). But embellishing or manipulating what happened ‘in order to enhance narrative drive... [or] make a more compelling story’ is a betrayal of an implicit covenant with the reader – namely, that the work is based on authentic experience, that the writer’s intent is to ‘write true’ (Gutkind 2008, p. 149; Perl & Schwartz 2006, p. 164). Aesthetically pleasing “truths”, and “truths” corresponding only to a vivid internal reality, are actually the prerogative of novelists (Mendelsohn 2010); ‘deceiving the reader is...inherent in fiction; in nonfiction its effect is poisonous’ (Ricketson 2010).

Truthfulness in creative nonfiction is guarded by a range of edicts, which are often expressed in uncompromising terms. ‘You can’t make it up’ (Gerard 1996, p. 5). ‘Do not add. Do not deceive’ (Clark 2007, p. 166). ‘Be absolutely sure of the facts’ (Wilkerson 2007, p. 174). If you are using somewhat controversial techniques, such as composite characters, ‘let your readers know what you are doing – and why. Your credibility is at stake’ (Perl & Schwartz 2006, p. 172). However, this advice is generally tempered for memoir writers, who may need ‘permission to lie’ in some situations: when memory has blurred the details, or when the narrative structure will creak unless details are condensed, or when a leap into conjecture is required to describe what has not been witnessed (Kupfer 1996). According to Roorbach, although verifiable accuracy in creative nonfiction is an important value, occasionally ‘it must hold the door for the greater values of drama and character, and the peculiar artistic force of memory’ (2001, p. 5). In life writing, sometimes the best that can be achieved is the intention to write truthfully, as the “godfather”⁵ of creative nonfiction, Lee Gutkind, explains:

all truth isn’t verifiable. This is especially important to acknowledge for those writing memoir. Ideas and feelings fished out of a person or unearthed from memory can’t be fact-checked. Scenes that are recreated, conversations that have been recalled and recounted from the distant past, will be highly personal and subjective.

⁵ Used pejoratively by critic James Wolcott (1997), the epithet was then adopted by Gutkind as a badge of honour

But in creative nonfiction we draw the line: We do not make up out-of-the-air information of any kind – for any reason. We do our best to replicate with truth and accuracy exactly what we believe has happened, even if, in the real world, there is a possibility that it hasn't happened in exactly the way we describe it or if other people disagree with our interpretations (Gutkind 2001, p. 176).

Like Polkinghorne and Gutkind, I regard truthfulness as a regulatory ideal. Truth may be complex, elusive, and susceptible to bewildering variation in terms of perceptions and interpretations, but nonetheless it is far too important and necessary a concept for it to be dismissed as unattainable. In setting out to write creative nonfiction stories about home-based palliative care, my intention was to make them as trustworthy, credible and true to life as I possibly could.

Obtaining ethics approval

The first hurdle to be faced in undertaking my research was to obtain ethics approval from the University as well as from the local area health service, Hunter New England Health. For some research projects, writing an ethics application appears to be a fairly straightforward process. This is not the case for topics relating to palliative care. I needed the approval of the health service because I was hoping that the community palliative care nurses who visited palliative care patients at home would help me get in touch with potential participants. The Human Research Ethics Committees and the community health nurses were, therefore, the people holding keys to the gates that needed to be opened before my research could proceed. I found that careful consideration of how to handle gatekeeping, beneficence, consent and anonymity became a fascinating exercise in applied ethics, one that fundamentally shaped the design of the entire project and its eventual outcomes.

Gatekeeping

Gatekeepers are those who possess the authority, formal or informal, to control access to a research setting (Neuman 2000). Overzealous gatekeeping is a well-recognised problem in Australian palliative care research, with a number of major projects subjected to lengthy delays due to difficulties in obtaining HREC approval (Masso et al. 2004). Researchers have reported that attempts to recruit participants were stymied by health professionals, who either failed to distribute

invitations to participate or cautioned potential participants against involvement (Fulton 1998; Hudson 2003a).

The desire to spare already burdened families further stress may be well-intentioned, but this paternalistic attitude denies people the right to make an informed decision about participation in such research (Hudson 2003a). Susan Lee and Linda Kristjanson (2003) argue that over-protectiveness regarding palliative care research is based on an outmoded view of patients as “dying” rather than “living with a terminal illness” and involves the belief that, in the words of a lay member of an ethics committee, ‘dying people should just be left alone’ (Lee & Kristjanson 2003, p. 14). However, one of the goals of the modern palliative care movement is to help people live as actively as possible until they die, which may include voluntary involvement in research aiming to increase knowledge and bring benefit to other patients and their families in the future (Lee & Kristjanson 2003). Interestingly, the updated *National Statement on Ethical Conduct in Research Involving Humans* now contains explicit acknowledgement of ‘the entitlement of those receiving palliative care to participate [in terminal care research]’ (National Health and Medical Research Council 2007, p. 62).

An excellent resource for aspiring palliative care researchers is a booklet funded by the National Palliative Care Program titled *Ethical Research in Palliative Care: A guide through the human research ethics committee process* (Masso et al. 2004). It warns researchers that HREC committees assessing palliative care research proposals may exaggerate psychological risks to participants in a way that overemphasises burdens relative to benefits. To counter this possibility, the booklet suggests that applications should cite studies demonstrating that participants do not experience the type of research being proposed as burdensome, and substantiate claims about potential benefits by referring to studies demonstrating that such benefits have been obtained (Masso et al. 2004).

In writing my ethics application I followed this advice by discussing empirical evidence indicating that most participants in palliative care research find the experience to be a positive one (Dyregrov 2004; Grinyer 2004; Hudson 2003a). Some people appreciate the opportunity such research provides to reflect upon, find meaning in, and come to terms with a major life event; and being able to contribute information that may be used to help others can become a source of

personal pride (Lee & Kristjanson 2003). A follow-up survey of participants who had been involved in longitudinal research whilst caring for a relative dying of cancer, found that almost three quarters experienced direct and indirect benefits and the majority (88.9%) reported no negative aspects associated with their research participation (Hudson 2003a). Anne Grinyer (2004) asked parental caregivers of terminally-ill young adults to contribute narrative accounts of their experiences and subsequently asked how their participation had affected them. Results showed that the parents valued their involvement, and many had found the process of recording their experiences was therapeutic. Their feelings of isolation had been reduced, and overall, they believed they had benefited from contributing to the study. As one participant wrote:

I am so pleased to have played a part in such an important and valuable resource. It helped to focus my own feelings and to put them into some perspective and release some of my innermost grief (Grinyer 2004, p. 1333).

The second, and perhaps more insidious, issue to consider with respect to gatekeeping is one that can surface after HREC approval to conduct the research has been obtained. Palliative care research often relies upon health care professionals such as nurses to distribute invitations to participate, because an intermediary who has regular contact with potential participants can introduce the research with less risk of provoking distress and anxiety than would a formal approach by a stranger (Beaver, Luker & Woods 1999). However, this means that the intermediaries are in a position to act as filters or even blockers of such research. Broback and Bertero (2003) noted that recruitment for their study of informal carers in Sweden had been impeded because district nurses felt uncomfortable using the term “palliative care” when talking to patients and next of kin, unless the patient was terminally ill and bedridden. Graham Fulton (1998) reported an extreme case of covert opposition from domiciliary nurses in his PhD study on the influences of discourse on illness experience. Despite a pool of 2,200 potential participants receiving nursing care from a particular service, only one person, who had been given an invitation by a relief nurse, approached him to volunteer to participate in the research project. She later withdrew when her regular nurse advised her that the research would be ‘of little value to patients’ (Fulton 1998, p. 103).

These examples illustrate the importance of convincing intermediaries that the research about which they are distributing information serves a useful purpose and that participation may be beneficial. How the intermediaries are introduced to the project's aims and methods, and the advice they receive about the type of language to use when telling potential participants about it, can have a large impact on how enthusiastically they engage with their recruitment role (Daniels & Exley 2001). Rather than assuming that health managers will convey all the right messages about the research to the people on the ground, it may be better to speak personally to everybody charged with distributing invitations to participate and address any concerns they may have. However, given the 'scattered, small service provision' characterising palliative care in Australia (Lee & Kristjanson 2003, p. 15), where each nurse in a district may only visit a handful of clients, personal contact with many individual nurses may pose an additional methodological challenge.

As my research was qualitative and did not require the recruitment of a large number of participants, I did manage to speak to nurses in Armidale and Guyra individually and in Newcastle at a group meeting. However, despite all my careful preparations, it proved impossible to locate and retain carers who were able or willing to be involved while in the middle of such a taxing time. In brief (more details are provided below), the two current carers recruited via the palliative nurses subsequently dropped out. Conversely, a publicity blitz involving newspapers and radio interviews in the middle of August 2007 resulted in twelve contacts, but all were from carers whose loved ones had already died.

Therefore, I revised the research documentation to include former carers, and submitted changes to the ethics committees. Instead of asking these participants to keep a contemporaneous journal, I asked them to write from their memories, or to find writing that they might have already done about this time in their life and share this with me. Soliciting narratives or chronologies from participants initiates the reflective process, as well as providing material that can be used as a starting point for in-depth discussion (Minichiello et al. 1995). The use of retrospective data has a number of benefits: the pool of potential participants is larger; the ethical issues are less complex; participants have more time to be involved and may be more inclined to focus on themselves and their experiences and feelings whereas previously they were focused on their loved

one; and finally, they have had an opportunity to assimilate what has happened to them and come to some understanding of their inchoate and often traumatic experience. After all, as Paul Connerton says ‘to remember...is precisely not to recall events as isolated, it is to become capable of forming meaningful narrative sequences’ (1989, p. 26).

Beneficence

Research involving the disclosure of sensitive or painful material may risk failing to uphold the ethical principle of beneficence. The term beneficence, when used in relation to research protocols, means aiming for a net beneficial effect, as well as aiming for non-maleficence, or ‘avoiding doing harm’ (National Health and Medical Research Council 2007, p. 99). Practically speaking, it refers to conducting research in ways that protect participants’ welfare, minimise the risk of harm to them and respect their privacy (Masso et al. 2004). It is generally assumed that encouraging people to talk about painful topics may cause them to suffer emotional distress; the standard precaution is to indicate this possibility on the information sheet for participants and provide contact details for counselling services. However, some researchers argue that there is no evidence that the level of emotional distress caused by talking about painful topics in a research interview is greater than in everyday life or that it requires any particular follow-up (Corbin & Morse 2003). Also, studies indicate that individuals appreciate the opportunity to tell their story to an attentive listener, even if they become upset whilst doing so (Dyregrov 2004).

Another risk for participants in palliative care research is that of being confronted with information that they are psychologically unprepared to handle (Haley 2002). Although families should know that they are receiving palliative care services, this does not necessarily mean that they accept the premise of palliative care: that their loved one is going to die. People can live in parallel realities, simultaneously understanding the terminal nature of the illness and yet still believing in the possibility of a miraculous cure (Kirk, Kirk & Kristjanson 2004). I knew from my own experience that caregivers may deeply resent statements loaded with assumptions about the inevitable trajectory of their loved one’s disease. My aunts never stopped thinking that somehow my mother would

be saved; a nurse who tried to engage them in practical discussion of what the family would be facing ‘further down the track’ received a coldly hostile response. In writing my invitation to participate and information sheet for participants⁶, I had to think carefully about what words to use to describe the health status of the patient. In contemporary literature, it is common to see the term “life-limiting illness” used in preference to “terminal illness”. This struck me as euphemistic jargon likely to be understood only by health professionals, so I chose to use “life-threatening illness” instead. Also, in any discussions with current caregivers that touched upon the sensitive issue of prognosis, I decided to ‘respect the need for hope’ (Kirk, Kirk & Kristjanson 2004) and let my questions be guided by the attitude they expressed in their solicited narratives.

Participants in palliative care research may also be vulnerable to unrealistic perceptions of the benefits of their engagement (National Health and Medical Research Council 2007). Careful communication is required to manage expectations in order to avoid disappointment later. I felt it was likely that I would find, as did Grinyer (2004), that family caregivers would invest a great deal of significance in the idea of a book that memorialised their loved one. However, I knew I might not be able to use all the material they gave me, or they might not like what I did with it. Also, there was no guarantee that the manuscript resulting from my research would be published as a book. I felt it was important to be clear and upfront about this in the information sheet and so I included the following warning:

You need to understand that I cannot promise that the book manuscript will be published. Nor can I promise that all the information that I collect will be included in the book or any other publication. Responsibility for the final form of the written products of this research rests with me and selection and reworking of material will be necessary. I will be identified as the author of any publications arising from the research and will have copyright of those publications.

Obtaining consent

A sense of desperation and obligation may impel palliative care patients to sign up for research: believing it represents their last chance to try a new cure, give something back to society or invest their situation with a redeeming meaning,

⁶ See Appendix 1 Invitation to Participate, and Appendix 2 Information Sheet for Carers.

they may agree to participate even if it is burdensome (Masso et al. 2004). Family caregivers may share this attitude. The research involvement of families receiving palliative care services must, therefore, be continually up for renegotiation as their circumstances and feelings will be volatile. The way to implement this is via process consent:

Process consent allows consent to be renegotiated at different stages of the interaction between the researcher and the participant. It is suitable for longitudinal approaches where participants are contacted on a number of occasions and consent needs to be re-established and renegotiated (Beaver, Luker & Woods 1999, p. 15).

My initial research protocol was designed to collect carers' accounts of their thoughts and feelings while they were actively engaged in caregiving. This made it important for me, as the researcher, to stress the non-binding nature of the agreement to participate and to be sensitive to any sign that a participant did not wish to continue (Masso et al. 2004). In the information sheet, after the list of things participants would be expected to do, I included the following caveat:

The best interests of your family are more important than the demands of this research, and you should feel free to stop, postpone or cancel your involvement in research activities at any time.

The only two current carers who signed up for my project did choose to take the option of withdrawing when the health of their loved one declined.

Dual consent

In addition to being sensitive to the possibility that participants might wish to renegotiate their involvement in the research at any time, I also had to consider that patients might not like the idea of their carer talking to me about their health situation. The Hunter New England Health Ethics Officer advised that my research would require two different information sheets and two consent forms, as the patient would have to agree to their carer's participation. In implementing dual consent, I had to decide whether the patient should have all the same rights as the carer. Should the patient (as well as the carer) be given the opportunity to review transcripts of interviews and edit/delete sections? I was concerned that this might inhibit the carer from speaking freely and would also compromise the confidentiality of their diary entries and interviews. Should the patient (as well as the carer) be asked to read pre-publication narratives and sign a release form?

Depending on the patient's state of health, this might be perceived as an onerous task. In the end I distinguished between those "participating" – the carers, and those "involved" – the patients, and the only thing patients were asked to do was read the information sheet and sign a form consenting to their carer's involvement.⁷ I left it up to the carers to decide whether or not to talk to their patients about what they had told me, or to show them their pre-publication narratives.

Choice of real names instead of pseudonyms

Conventionally, researchers protect the anonymity of participants and the confidentiality of their information by disguising personal identities in publications (Neuman 2000). Consent forms often include a statement such as: 'I agree to publications based on the research data, provided that my real name is not used.' However, as the purpose of my data collection was to produce vivid, true-to-life creative nonfiction stories, rich in potentially identifying detail, I felt strongly that it would be impossible to guarantee that someone who knew the family being written about would not recognise them, even if names and places were changed. The new section on qualitative research in the *National Statement* makes it clear that just promising to use pseudonyms may no longer be sufficient:

Participants are often easily identifiable... and the information they provide may be sensitive. For these reasons, care should be taken that participants are not identifiable by the information they provide, unless they have agreed to be identified... participants should be informed about any potential to be identified in the results of research even if identifiers, such as name and address, are removed (National Health and Medical Research Council 2007, p. 28).

The Hunter New England Health HREC application guidelines I used stated that prior to publication of material containing potentially identifying information, participants needed to sight the intended use of their data and sign a release form⁸ (Hunter New England NSW Health 2005). Therefore, my information sheet said:

The descriptive and detailed nature of the stories I will be writing make it difficult to promise that participants will be anonymous. I can disguise names, dates and locations, but cannot guarantee that someone who knows your family circumstances will not be able to recognise you in the stories.

⁷ See Appendix 3 Information Sheet for Patients, and Appendix 5 Consent Form for Patients.

⁸ See Appendix 6 Release Form.

I will use your information in the book manuscript and thesis for my PhD, for conference papers and for articles in scholarly journals. Prior to submission of the PhD, you will be offered drafts of writing based on your material and showing its usage in context. You will be invited to suggest modifications or request deletions before signing a Release form. If a mutually satisfactory version of the writing cannot be negotiated, you will be completely free to withdraw your contribution. If you want real names to appear with your material in the publication you will have to nominate this option on the Release form, otherwise pseudonyms will be used.

Note that the last sentence in this excerpt from the information sheet mentions that participants could elect to have their real names used, rather than pseudonyms. Some research participants prefer to waive anonymity in order to “give voice” to their personal experience (Giordano et al. 2007). They may feel that they ‘lose their ownership of the data’ when they are anonymised (Grinyer 2002). Three quarters of the thirty participants in Grinyer’s study – parents who contributed narratives about the experience of caring for an adult child with cancer – opted to have their real names published, and spoke of the book as a lasting memorial to their son or daughter (Grinyer 2002, 2004). In my study, only one family opted to be represented by pseudonyms.

The issue of negotiating a ‘mutually satisfactory version of the writing’, also mentioned in the excerpt above, is integral to my project and will be discussed in the section below and also in Chapter Four.

Conducting the Project

Recruitment

To be involved in my study, people needed to be a primary caregiver, currently, or in the past, for a person living at home receiving palliative care services. Recruitment began in July 2007 via the local palliative care nurses. Response was initially slow; two carers expressed interest but both subsequently dropped out when their loved one’s condition deteriorated. In conjunction with a journalist from UNE’s Public Relations unit, I wrote and distributed a press release about my research which was published in the *Armidale Express* (13 August, 2007) and the *Armidale Independent* (22 August, 2007) and which resulted in two radio interviews, one with Carol Duncan of ABC Radio Newcastle (14 August, 2007) and one with Suzanne Hill of ABC Radio New

England North West (15 August, 2007). As a result of this publicity, I received twelve email and telephone expressions of interest from ex-carers and sent information packages to all of them immediately. Two people progressed to the first interview: one decided to drop out because she felt her mental health too precarious to relive such a painful time, the other continued to the end of the study.

In the end, it was a combination of media coverage, word-of-mouth and personal networks that succeeded in recruiting the people whose stories appear in 'A Hospital Bed at Home'. Robin, a friend from my book club, spoke to Katherine about the project and with her permission passed her contact details on to me. Kaye heard about it via Siobhan, a fellow postgraduate researcher whom I had met at the ANU *Using Lives* workshop. Maxine, my homebirth midwife, saw the article in the paper and told my husband she was willing to be involved. A chance encounter with Rebecca in the University of New England gym led to her becoming a participant. And Ben and I had met as carers at Petrea King's Quest for Life program, and after reading part of his story on the web and tracking down his address, I sent him a personal invitation, which he accepted.

All of these carers had looked after a husband, wife, father or mother who was suffering from a malignant disease – cancer of the lung, brain, ovary, prostate, blood or breast. Patients with progressive neurological conditions, end-stage heart, lung or kidney failure, or HIV/AIDS, could also have been included; however, such non-cancer patients currently account for a small proportion (only 10-15%) of palliative care services (Hardwick 2009), so it was not surprising that cancer predominated among the patients in the stories.

The recruitment process was undeniably opportunistic, however I did exercise a degree of choice. The information sheet noted that I was 'looking for carers from a range of backgrounds (for example, men and women, various age groups, people from rural, regional and urban locations)' and would not necessarily be able to include everyone who wished to be involved. I deliberately sought male carers but found them harder to recruit and retain than women. Ben's story is the only one featuring a principal carer who is male; however, men who made a significant contribution as carers do appear in several of the other stories. For instance, Katherine's brother Don; Gerard's bikie friend, Charlie; and my own brother, Michael. In terms of geographical spread, my location in a

country town certainly exerted an influence, but I did get one urban carer (Kaye from Melbourne), two located on the coast, and even one case where an expatriate carer went to Northern Ireland to take up her role.

Apart from seeking variety among the types of carers, I also sought something less easily definable. During the initial conversation with a potential participant I was listening for characters and circumstances that held the promise of an interesting, engaging story. If I found myself feeling moved, intrigued, outraged, full of questions, eager to learn more about what they had been through, I knew I would be able to fashion something from their experiences that would be worth reading. There was only one case, toward the end of the project, where a participant was willing to continue but I felt, after five hours of interviews, that his story was thematically very similar to one I had already written and that his account lacked the level of detail I required. Fortunately, he genuinely did not seem to mind whether we proceeded or not.

Gathering material

Narrative research can be time-consuming, because the researcher needs to collect extensive information from, and about, each participant in order to develop a contextualised understanding of their life experiences, and then must find some way of structuring (“restorying”) this material in order to produce an engaging narrative with a beginning, middle and end (Creswell 2007). In creating my stories for ‘A Hospital Bed at Home’, I drew upon a wide range of resources. I wrote detailed notes after each conversation I had with participants, especially if it had not been recorded. I collected whatever documents people were prepared to share with me, which included retrospective accounts varying in length from two pages to twenty, photocopies of journals kept by the carer or the patient, photographs, letters, advance care directives and texts of eulogies and tributes delivered at the funeral. For my own memoir, I had several years’ worth of daily diary entries stored electronically, as well as some paper-based diaries that my mother had kept sporadically. I also searched the internet for extra details about people and places, and the participants and I exchanged numerous emails when refining the details of each story.

Interviews lasted from one to two hours and usually began with a discussion of written material, either something the carer had written, or the current draft of the story that I was writing. Apart from having such material as our starting point, the sessions were more like a conversation than a structured interview, with the discussion unfolding in a natural, open-ended manner, as is typical of narrative inquiry (Clandinin & Connelly 2000). I interviewed each carer two or three times, mostly in person but sometimes via telephone. The face-to-face interviews were held wherever was most convenient for the participant. Generally, this was at their home, which was ideal as it allowed me to incorporate description of the place of caregiving into the story. Rebecca, whose caregiving had occurred in Northern Ireland, met me once at a university café and twice at my house (which, as it turned out, she was quite familiar with, having been a close friend of the previous owners). The interviews were recorded, with permission, on my small Olympus WS-100 digital voice recorder. This allowed me to accurately preserve what was said without extensive note-taking, and freed me to engage normally in the conversation in terms of eye contact and facial responsiveness. A telephone pickup device which connected to the voice recorder allowed me to capture both sides of the interviews that were conducted on the phone. The files were later transferred to my computer and fully transcribed, a process which took roughly five hours of typing for each hour of conversation. Interviews were usually held a month apart, to allow for transcribing and drafting of the story between them. The first two interviews would be the longest, each generating transcripts of up to 15,000 words; the third interview was usually devoted to negotiation of the content or points of clarification.

In almost all cases, I spoke to other people who had been involved in the caring, or received extra information or feedback from them, always with the permission of the principal carer. However, I made it clear that I saw myself as having one main informant for each story, and that person was the one who had the final say about inclusions and exclusions. Material from others was supplementary and designed to enrich the account, not aimed at presenting a conflicting or opposing point of view. Rebecca's story was the only one where input was not sought from close family or friends. She did consider asking her mother and her sister to participate but eventually decided she would not. She felt

that her mother was still too distressed to speak about the death of her husband, and that her sister's set of experiences had been different to her own. As an experienced qualitative researcher herself, she understood what was at stake. In an email, she wrote: 'I have been thinking that this is my perspective – my story, my meaning-making process, so to ask Verity to contribute would dilute that and really, she has another story to tell – do you see what I mean?' (Rebecca, pers. comm. 13/02/2009).

Writing the stories

In terms of elapsed time, each story took an average of nine months to complete, from the initial contact with the participant to the final agreement that we had finished, and each ended up being around 6,000 words long. I tended to have several in train at any one point, at different stages of completion. The following timeline traces the development of 'Retreat to the castle' and 'No big deal' over the period from August 2007 to July 2008:

21/08/07

First contact with Katherine: phone conversation lasting about forty minutes. Unrecorded, notes taken. She agreed to do some writing for me.

18/09/07

First interview at Katherine's home, one hour, unrecorded as she seemed nervous about participating. She gave me four pages of recollections and the signed consent form. I dictated 3,000 words of notes into my voice recorder as I drove home.

20-25/09/07

Began writing 'Retreat to the castle'.

4/10/07

First contact with Maxine: phone conversation lasting about twenty minutes. Unrecorded, notes taken.

9/10/07

Katherine rang to withdraw from the project, citing family concerns about Hugh's privacy, but agreed to look at my 2,500 word draft of the story first.

12/10/07

Katherine decided to continue participating.

16/10/07

Second interview at Katherine's home, two hours, recorded except for initial fifteen minutes spent discussing how we would work together. She showed me the family set of advance care directives, and gave me a photocopy of Hugh's one page obituary from the local newspaper.

17/10/07

Three hour interview at home of a participant who later withdrew, recorded but not transcribed.

25/10/07

Finished transcribing Katherine's interview.

2/11/07

First interview at Maxine's home, two hours, recorded. She gave me the signed consent form, showed me photos taken before and after Gerard's death and her handwritten journal. Most of the entries were for June 2003 (diagnosis) and October 2003 (death). She photocopied about twenty pages and posted them to me with some sections cut out or blacked out.

10/12/07

Finished transcribing Maxine's interview.

18/12/07

Emailed Maxine first draft of 'No big deal'

21/12/07

Second interview at Maxine's home, ninety minutes, recorded, with herself and daughter Sujata.

11/02/08

Emailed updated version of 'No big deal' to Maxine.

15/02/08

Emailed updated version of 'Retreat to the castle' to Katherine.

18/02/08

Received encouraging feedback from both Maxine (phone) and Katherine (email) regarding the stories. Maxine agreed I could seek input from friends who helped care for Gerard, and Katherine said her brother had agreed to write his thoughts down for me.

25/2/08

Third interview at Maxine's home, one hour, recorded. She gave me a signed release form opting for real names.

29/02/08

Workshopped both stories with fellow creative writing postgrads Helena and Peter. Revised them before emailing to supervisor Donna for comment.

March 08

Conversations with various local friends of Maxine's who had assisted with caregiving, all unrecorded except for a 40 minute interview with Beverley, at her home.

21/03/08

Third interview at Katherine's home, one hour discussing story modifications (unrecorded), another hour recorded. She gave me a copy of a two page 'family update' letter written by Hugh on 15 January 2005 and a two page eulogy written by one of his sons.

24/3/08

Emailed updated version of 'Retreat to the castle' to Katherine.

2/04/08

Emailed updated version of 'No big deal' to Maxine.

3/04/08 – 16/04/08

Exchanged at least a dozen emails with Katherine and her adult children regarding suggested revisions to the story.

30/05/08 – 11/06/08

Various email/phone contacts with Katherine regarding the implications of signing the release form before she posted it to me, opting for false names.

5/07/08

Received email from Maxine verifying that the final version of the story was fine.

Getting Started

In sitting down to start writing the first story, I was undoubtedly influenced by the fact that I had just finished reading Peter Rose's (2001) award-winning family memoir about suffering and devotion, *Rose Boys*, and had been immensely impressed by the emotional power and elegance of its understated tone and its beautiful, simple prose. *Rose Boys* opens with Peter looking through old newspaper clippings about his brother Robert's car accident. The headlines shout: 'ROSE PARALYSED IN CAR ROLL'; 'CRICKET, FOOTBALL STAR IS PARALYSED'. In order, the chapter titles and my own abbreviated, bracketed take on the contents are:

scrapbooks [metre high records of family fame]
st valentine's day [the accident]
rambling rose [Robert as a wild boy]
ward 7 [aftermath of the accident]
scoop [limited recovery, working as a sports journalist]
the bunker [area of Rose family home where Robert and wife Terri lived]
yarra me [the hostel Robert moved to after Terri left him]
intensive care [the final gruelling months of Robert's life]
the banner [funeral and memorialising]

The skeleton outline I drew up for 'Retreat to the castle' deliberately mimicked the condensed nature and non-chronological structure of this table of contents, even down to the lack of capitalisation:

Outline: Baden story
ban: Hugh's announcement that he wanted no non-family visitors.
man: personality. Fold in information about illness
load: legal arrangement. Effect on Katherine. Kids – money offer
support: the blokes. Baden's don't pay. Weekends. Bereavement group?
final weeks: the brother
crystallization: the manner of death reveals the man

Like Peter Rose, I decided not to be strictly bound by chronology in presenting my stories. I wanted each to have an arresting opening – the background information could be folded in later, after the reader’s interest had been engaged. Textbooks about writing creative nonfiction often recommend the literary technique of presenting events out of sequence. Philip Furia talks about exorcising the three demons that haunt biographical writing: the first is too much material; the second is losing the plot; the third is the dead hand of chronology. He says that ‘the day-by-day, year-by-year, narrative pattern of most biography needs to be reimaged’ (2001, p. 76) and for inspiration he recommends documentary films which are highly selective about the footage chosen, use flashbacks, and preserve suspense in the narrative. Lee Gutkind’s classic text, *The Art of Creative Nonfiction* notes that starting a story ‘as close to the heat of the action as possible is the best way to involve readers and compel them onward’ (1997, p. 55). Finally, in *Writing Creative Nonfiction*, Theodore Cheney advises that beginning *in medias res*, with a scene that belongs elsewhere in the story is perfectly acceptable, citing how *The Right Stuff* (Wolfe 1979) opens at a point where a young fighter pilot’s wife is waiting to hear if his plane has crashed:

Wolfe didn’t open by telling us that he was about to tell the story of the astronauts’ lives; he didn’t tell us about the structure of NASA or the Navy fighter pilot training program; and he didn’t tell us that Pete Conrad would survive to become an astronaut. Wolfe took us first into the compelling emotions of a twenty-one-year-old wife of a twenty-year-old fighter pilot as they began married life, a life that would bring to her many moments of terror. The result? We’re immediately involved. We’re not concerned about all the background. We can’t become interested in the astronaut training program until we become involved at a human level with the people participating in it (Cheney 2001, pp. 154-5).

In line with such recommendations, each of my stories commences with a scene encapsulating the main thrust of what is to follow, regardless of where it appears in the actual timeline. For ‘Retreat to the castle’, it is the image of longstanding friends being turned away. ‘Don’t even come up the driveway,’ Katherine warns them. ‘It sets the dogs off and Hugh gets angry and there’s enough stress in the house already.’ ‘No big deal’ opens with Gerard’s serene acceptance of a fatal brain tumour, and how puzzling it was for those who rang to inquire about his health to hear the jubilant response: ‘I’m wonderful! I’m so good! How are you?’ ‘Three steps behind’ depicts how odd I found it to hear Ben request ‘a list of

every emotion a person could experience' during a meeting at the Quest for Life centre. 'Staying happy' presents Kaye lying to her husband about why she is staying home from work, so he won't realise that his death is imminent. 'I just cannot' starts with Rebecca telling me about her caregiving in Northern Ireland, describing how she found herself mediating between Daddy, who could not, or would not, eat; and Mummy, who was angry and bewildered and kept on trying to feed him. And my own story, 'Keeping on', begins at the point where I find out my father has committed my mother to a palliative care ward because, as he put it: 'She's a lot of bother at home, Janene. You've got no idea.'

Quoting

As I worked on each 'Hospital Bed at Home' story, I had in front of me the transcripts of my recorded interviews, but where necessary I rearranged, cut, and smoothed the speech as it had been spoken to sharpen it and turn it into an acceptable written text. However, while doing this I always tried to keep faith with the distinctive voice of the speaker and the intended meaning. Not everyone agrees with the practice of tampering with quotations. In her article 'Hearing our subject's voices: Keeping it real and true', Debra Dickerson states: 'I don't think that quotes should be sanded smooth; quotation marks mean that what is enclosed in them is verbatim' (Dickerson 2007, p. 107). But I think it is naïve to assume that spoken testimony, with all its pauses, repetitions, sentence fragments and false starts, is a better representation of actual meaning than reconstructed speech, especially if the interviewee is subsequently invited to review the final text. Dickerson admits that some of her interviewees have been incensed by how 'ignorant' she makes them look. In common with other writers, including prominent nonfiction author Helen Garner, I believe it can be both unkind and inelegant to print the raw sentences that fall from the mouths of the people you are interviewing:

The way people speak makes me dizzy with joy – all those curls and leaps and sudden silences. But there's a great art in quoting. My hero, the American writer Janet Malcolm, is brilliant on this in *The Journalist and the Murderer*: 'Only the most uncharitable (or inept) journalist will hold a subject to his literal utterances and fail to perform the sort of editing and rewriting that, in life, our ear automatically and instantaneously performs.' The art of it is in choice, but also a kind of inspired and totally legitimate mimicry. And there are times you have to

paraphrase, or the reader will die of boredom (Helen Garner quoted in Eisenhuth & McDonald 2007, p. 163).

As Philip Gerard says, it is possible to use sound judgment and craft to capture truth that is exact but not entire and not verbatim. ‘Because you’re not a stenographer. You’re a writer’ (1996, p. 75).

Positioning the narrator

Despite the consultation that occurred throughout the writing process, the stories do not speak with the ‘cloven tongue’ of collaborative autobiography, where the narrator takes on the persona of the subject and tries to ghost-write their thoughts and feelings (Couser 2001). Rather than a negotiated first-person telling of each story, there are multiple, distinctive voices. The experience of the main character, the primary caregiver, is related through a mixture of quoted speech directed at me as the listening presence, and via passages of summary and explanation narrated in the third person. I appear in each story in the first person, making the occasional comment prefixed by “I”, and of course the narratorial voice doing the summarising and explaining is me, too. This is not unusual in creative nonfiction: the difference is that my presence as a character is minimal and the spotlight is on the person talking to me.

Lee Gutkind did something similar in his story about a woman whose husband made a barter arrangement with the local dentist to have all her teeth pulled out and replaced with false ones, even though her own were perfectly healthy. It appears in the anthology *Connecting* and is prefaced by these editorial remarks, also written by Gutkind:

The creative nonfiction genre permits – even encourages – the writer’s voice, point of view, and involvement. But essays don’t require a writer’s active presence and, in fact, can be weakened by it. The unique quality of this essay is that the writer has recognised and embraced a character with a story and established himself as a willing listener, waiting for the story to be told. From beginning to end, the reader hears the protagonist’s voice – but visualises the action through the subtle filter of the writer’s perceptions and interpretations (Gutkind 1998, p. 211).

It heartened me to find this quote from Gutkind, as a fellow postgraduate at the *Using Lives* workshop had questioned whether I would actually be writing creative nonfiction. Based on my presentation, she said it didn’t sound as if the stories I planned to write would have the strongly subjective authorial voice that

she saw as one of its defining characteristics. Initially, I felt demoralised by this assessment, but when I raised it with the other students later, one suggested that stepping back to let my participants speak unimpeded could be a strength rather than a weakness:

I'm wary of writing that puts 'I' all over the place – many of the things that I've read with a lot of 'I' does become self-indulgent... Shouldn't your personal knowledge in a way 'inform' or be the 'intelligence' behind your work... does it need explicit statement?... and the other thing is, you don't want to 'use' other people's stories merely as a means of telling your own – don't you want to give them a means to speak their own story? (Helen Gildfind, pers. comm. 20/09/2007).

In a similar vein, Gerard (2001) argues that too many writers of nonfiction 'enter the story whether it needs us or not', thereby diverting attention from the real star of the piece and running the risk of distracting or even annoying the reader. He suggests that sometimes writers should be content to participate via tone of voice, which implicitly conveys an attitude and a moral stance:

Even without an "I" narrator, we can hear it when an author doesn't approve of something, or finds it humorous, or is awed or confused or sceptical. Tone, as we experience it in the lines and between the lines, tells us the author's sense of right and wrong, his sense of proportion and outlook on the world. It's the reason we either trust a story or don't, either turn away in irritation or remain captivated (Gerard 2001, p. 52).

While writing each 'Hospital Bed at Home' story, I was aware of the points of similarity and difference with my own experience, but generally I managed to refrain from leaping in and out of the text proffering comparisons. I decided that as I had been fortunate enough to find generous, intelligent people willing to share their thoughts with me, it would be counter-productive and churlish to turn myself into an intrusive authorial presence. My own reflections on being a carer would stand alongside the others – as snippets woven between the individual stories and as a full and frank memoir at the end.

Showing drafts to participants

As noted in the section on obtaining ethics clearance, admitting to Hunter New England Health that people would probably be identifiable in my richly descriptive stories activated certain safeguards relating to informed consent. The HNEH application guidelines stipulated:

Information which might identify participants is not to be disclosed without their prior consent. This is particularly important for interview, oral history, focus group, imagery or performance data, where individuals might be quoted or directly or indirectly identified. Explicit consent is required in this case and participants must be able to sight the intended use of their material before granting a Release or Consent (Hunter New England NSW Health 2005).

Showing participants a full draft of their story prior to publication was compatible with my desire to be non-exploitative and non-maleficent in conducting the project, but asking them to sign a release form effectively handed them the power of veto at a very late stage. I worried about negotiating a ‘mutually satisfactory version of the writing’ under threat of losing months of intensive work if the participant did elect to withdraw. As discussed in the previous chapter, many biographers, creative nonfiction writers and even narrative researchers would regard this as a threat to my writerly integrity. Perhaps all the stories would turn out to be sentimental portrayals of courageous patients tended by devoted and self-sacrificing family carers?

Fortunately, this did not prove to be the case, despite – or perhaps because of – the fact that my working processes ended up being very collaborative. I did not just take a finished story back to the respective participant and negotiate changes at that point. Instead, we became involved in an iterative cycle of interviews, each one incorporating the participant’s feedback about how my current draft was shaping up as well as introducing new material that revised, extended, and deepened what I had written so far. People got to see what I was doing with their information at an early stage and found they could trust me not to judge or criticise them. The richness of what they were telling me was progressively enhanced, as was my understanding of its nuances and complexities. That said, I did not plan this way of working, and have never particularly liked sharing drafts of my writing. It began when one of my early recruits, a woman with a fascinating story, was on the verge of dropping out and the only thing I could think of doing was to show her what I had written based on our first interview. The draft was sketchy and full of gaps, but reading it persuaded her to stay with the project.

When a mutual acquaintance first spoke to me about Katherine’s situation, I got the impression that her sick husband had been a tyrant, allowing no one in the house to nurse him but his wife, who had been run ragged caring for him in

the six months before he died. At my first meeting with Katherine, it soon became clear that she had not regarded Hugh as a tyrant at all. Her rationale for his behaviour was enlightening and convincing. I went home and composed a first draft of the story, writing it in a way that respected her understanding of his personality and her perspective on what their relationship had been like. Thus, I had something to show her when she telephoned to say that she wanted to drop out because her adult children were not happy about exposing their father to public scrutiny. They were concerned that his attitude to visitors in his last few months left him vulnerable to criticism and wanted to protect his privacy. Katherine seemed to feel some remorse about letting me down but naturally family harmony was more important to her. I suggested that she look at the rough version of the story before she made a final decision. She agreed to do that, so I emailed it to her. When I contacted her a few days later, she said she was thrilled by the story. She thought it was ‘brilliant’ and had shown it to her children and persuaded them that involvement in my project was not going to result in the besmirching of Hugh’s reputation.

To craft a story about someone else’s experiences, to shape a jumbled assortment of recollections and anecdotes into something readable, inevitably involves filtering the material through the mind of the writer, as noted by Gutkind in his editorial preface to ‘Teeth’ (1998). Although this interpretive filter may be unavoidable, I believe it is possible to mitigate its effects, to some extent, by giving subjects a say about how their lives appear in print. Furthermore, such negotiations can enhance rather than diminish the text. When given early drafts to review, participants corrected my errors and misapprehensions, they gave me extra information to fill in sections that were sketchy, and they confounded my simplistic versions of what had happened by supplying more complex details. Occasionally, reading the draft prompted them to remember a fresh anecdote that could be incorporated to round out the narrative. For example, my third interview with Katherine netted a thousand additional words for a story that I had thought almost finished, and left me feeling utterly exhilarated, as my diary entry for that day reveals:

21 March 2008

*Spent 2 hrs with Katherine. Details came tumbling out of her, she even had some documents to give me and she had the biblical reference I needed. I felt like someone who could see a gold seam opening up before them. I now understand why looking after Hugh was so debilitating – it was the hallucinations – they have to go in, along with Kerry's remark that in spite of being at home busy and tired with three under five, she was in paradise compared to her mother. More stuff came out about the dinners Don made (Katherine hates Mexican food!) and the brothers' visits. All great material!*⁹

On the whole, my negotiations with participants proved amicable and fruitful, and each case had a happy ending in that everybody did sign the release form agreeing the story I had written about them could be published. Rather than threatening my writerly integrity – as I had initially feared – I ended up deciding that the ongoing consultation and negotiation had made the stories infinitely richer. Living through this process also leads me to suspect that collaboration at the rough draft stage promotes the most useful kind of feedback, and to wonder if participants who are only asked to comment on a polished final version might perceive the text as immutable, less open to revision.

None of the foregoing is meant to imply that all of the negotiations were sunny and free of tension. The occasional fraught moments involved in getting to an acceptable final version and a signed release form are discussed in the following chapter.

⁹ This material is incorporated in the manuscript at pages 14, 16, 17 and 18

Chapter Four

DISCUSSION OF OUTCOMES

Whenever I presented my work-in-progress at seminars and conferences, I found rhapsodising about the benefits of the consultative methods I was using would invariably provoke somebody to raise the issue of potentially irreconcilable divergence and disagreement. In this chapter, I describe how particular instances of conflict were handled and the often anxious process of negotiating a final version of a story that would be acceptable to all concerned. I also discuss how working with memories of difficult, painful times affected me, as a researcher, writer, and memoirist, as well as reporting what participants said about how the project affected them. Finally, I acknowledge how the habit of working consultatively has shaped my subsequent practice of journalism.

Negotiations

In writing this chapter, I have drawn upon the electronic journal I kept throughout the four years of doing my PhD. Into its capacious, date-ordered, fully-searchable storage system I tossed all my plans, questions, musings, worries, insights, lists of must-read books, and, most importantly, full records of the interactions I had with my research participants. From this I have been able to construct some “confessional tales”, John van Maanen’s (1988) term for ethnographers’ reflective accounts of the problematic feelings and difficult situations that they encountered in their dealings with the people they were studying. Such candid outpourings can be an enlightening and entertaining guide to the vicissitudes of research as it is lived, as this extract from the diary of renowned anthropologist Bronislaw Malinowski illustrates:

Yesterday I slept very late. Got up around 10. The day before I had engaged Omega, Koupa, and a few others. They didn’t come. Again I fell into a rage. (Malinowski 1967, p. 67).

Although I did not tend to fall into rages over the behaviour of my participants, working with them did cause me considerable anxiety. What if the person didn’t

like what I had written? What if they demanded changes that I was not prepared to make?

Soliciting feedback from subjects prior to publication is regarded by many nonfiction writers as a risky practice because, when faced with their words on the page, the person may want to retract the interesting admissions and sensitive details that had surfaced during the course of the interview (Gutkind 1997). But as Gutkind notes, it can be hard to predict what aspect of the text will touch a nerve with your informant – often it can be something that the writer regards as trivial. I found that when one of my participants asked me to amend or delete some detail (not because it was inaccurate, but because on reflection they regretted having mentioned it) I generally had no difficulty in complying. On the few occasions where I felt sure that acceding to their request would weaken the story, I explained why the statement needed to stay as it was, and managed to convince them.

However, I do not think I could have negotiated a radical shift to what I had decided was the main thrust of the story without compromising my writerly integrity. As noted in Chapter Three, some situation or attitude I found fascinating and distinctive would emerge during the initial conversation with each participant. This aspect would be explored in our subsequent interviews, and if confirmed as a useful and valid way to approach the story, would be incorporated into the opening scene to captivate readers as well. If, after reading an early draft of the story, a participant had strongly objected to the angle I had taken, I suspect it might have derailed the whole process of working together.

There was one case where a participant's reservations about what I had written almost did lead to a breakdown in communication. Unlike the other stories, I gathered most of the material for 'Three steps behind' before sitting down to write it, so Ben did not get to read any incomplete drafts between interviews. This was partly due to unfortunate timing (our phone conversations in April and our afternoon at his home in May coincided with me presenting at a conference, writing a journal article, finalising Katherine's story and recruiting Rebecca, so I did not finish transcribing Ben's material until June); and partly due to the fact that by our second interview I could see it was going to be difficult to produce a story that Ben would not find confronting. We agreed on the angle – how an already fraught relationship was tested by the demands of

terminal illness – but Ben seemed to believe that idiosyncratic deficiencies on Lynne’s part could explain much of what had gone wrong between them. Based on what he told me about their shared history, I could see plausible alternative interpretations. I felt that some of his explanations had a self-aggrandizing bias, and that I would have to find a way of incorporating into the story a countervailing point of view:

18 April 2008

Listening to Ben last night, so smug, so focused on what he wanted to achieve and his progress to date, talking about Lynne’s failures in the areas of health, career and motherhood, made me feel so sad for her. She sounded shackled by the small children that cemented their relationship, not even able to imagine her way out, the life she hadn’t even started living so cruelly cut short.

Of course, I could not write the story in a way that would take sides or be overtly critical of my main informant. Ethically (treating participants with respect), pragmatically (being committed to negotiation) and stylistically (show, don’t tell), making judgmental statements was out of the question. But neither did I want to simply take Ben at his own valuation and present only his version of what had happened, completely effacing Lynne in the process. I wrote several drafts and requested feedback from a number of readers before I felt reasonably happy with the balance and the tone. Then I sent it to Ben with some trepidation and a note saying I was keen to talk soon about any changes he wanted to suggest, anything I had misunderstood or got wrong, or things he thought needed to be added.

I got no reply to this email or to the message I subsequently left on his phone voicemail service. Five days passed. I rang several times but did not catch him at home. Then, one evening at about 9 pm, Ben called me inadvertently:

12 August 2008

Ben said he’d received a call from our number and was returning it to see who it was. We had a funny conversation – he said he hadn’t opened the email and he’s ‘too busy’ to read it for the next few weeks. He’s renting a space for a clinic in town and gearing up to open it, says he’s frantic trying

to get it ready by the end of this month. Not sure why he'd be bothering to return stray calls in that case. I can't understand how someone could be so lacking in curiosity as to not want to read a story about their life someone else had written? Of course I'm worried that he has read it and hated it, but doesn't have time to work out how to tell me.

Anxious and puzzled, I asked my husband Chris for his perspective on the situation, as a male. His interpretation was that perhaps Ben had regretted speaking to me, had waited with some foreboding for the result, and had found my 'look at this and comment' request intrusive, something he would prefer to ignore.

With this in mind, I waited several more weeks before sending a carefully worded letter to Ben. I will quote the letter in full and then cast a critical eye over what it says, and what it fails to say:

1 September 2008

Dear Ben,

I'd like to start by apologising if I seemed to be placing too much pressure on you last month for a quick response to the story. I appreciate that you have enormous demands on your time and I am grateful for the help you have given me so far. I hope the business expansion you've been working toward is going smoothly and turns out to be a great success.

I think I mentioned that I will be going to the NSW State Palliative Care Conference in November? I'm planning to read from the stories and I would love to be able to include a section from yours. The people who have read it so far – my supervisor Donna and two fellow students from my writing workshop group – have commented that they found it very moving and powerful. Also, as you know, the perspective of the male caregiver is one that is not often presented.

However, before I can use the story in any way, I need your signature on the enclosed Release Form, and for you to choose between real names and pseudonyms.

I'm more than happy to discuss revisions of the story with you, now or at some point in the future, or I can proceed without active feedback from you, if you prefer.

Sincerely,

Janene Carey

Firstly, although the tone is friendly, there is a certain formality in the wording and the presentation (doubtless I printed it on university letterhead) that would have served to remind Ben he was involved in a research project on a topic we both regarded as important. I reinforced the significance of his participation by mentioning my desire to present the story at a forthcoming conference as an example of a male caregiver's perspective. Ben is a person who often discusses opportunities to "contribute" to the welfare of friends and the goal of "making a contribution" to society in general. So, I was appealing to his altruism and his generosity. Secondly, I accepted and even validated his excuse of being "too busy" to respond, and made no mention of the possibility that the draft of the story had distressed him, even though I suspected this was the case. Therefore, I made it harder for him to discuss other reasons for his non-responsiveness. Finally, I presented him with two options: we could work on revising the story, now or later, or he could just sign the release form. I did not remind him of his right to 'withdraw from the project at any time without giving a reason', nor did I point him to the sentence in the information sheet that mentions the option of 'withdrawing the written and spoken information you have provided'. Why not? Because that was the outcome I most wished to avoid, having invested months of effort to get the story to this point. Also, I did not want to imply that severing our connection, without any attempt to talk things through, was acceptable to me. We had a relationship that predated our researcher-researched one, and I think neither of us would have wanted it to end on a sour note.

With hindsight, I think that I failed to recognise how 'the dynamics of persuasiveness, personality and power' might have been working in my favour and casting a shadow over what, ideally, would have been an authentic conversation (Josselson 2007, p. 552). The letter should have at least canvassed the possibility that Ben might have experienced the story as hurtful, and

explicitly assured him of my goodwill. It should have reminded him of his inviolable right to withdraw himself and/or his material from the project, while making it clear that my strong preference was for us to keep working together. I think I could have communicated with Ben more honestly and more ethically in this letter, and still achieved the same outcome.

A week later I received an email saying he had finally managed to read the story. He thanked me for my efforts and said he could see the work involved. He mentioned a couple of things that he thought might be too private to include, and wondered if he was ‘painted as a bit heartless and too career-focused’. He said he would need to look at it again and he didn’t feel ready to talk about it yet. I emailed the following reply:

Dear Ben,

Thanks for this honest response. You need time for reflection so best to let it sit for a week or two and we can discuss changes after that. Briefly, though - events from your earlier life that you don’t wish to make public – like [material excised] – are easy to remove as they’re not essential to the caregiving story. And I certainly don’t wish to paint you as heartless! Career-focused, yes, but many men are and so are quite a few high-achieving women I know. The pressures of work and family are most intense when children are little. I think the tragic thing about this story is the timing – you get the sense that the relationship problems would have sorted themselves out within a few years as the kids got older.

talk soon – warm wishes,

Janene

This seemed to have the desired effect of sounding reassuring without promising to radically overhaul the story, because Ben replied thanking me for my ‘words of wisdom and insight’ and fondly recalling our walks at the Quest for Life Centre. Nonetheless, five more weeks passed without him managing to find time to reread the story and mark up the areas that he was unhappy with. We’d had one phone conversation in the interim, during which he had indicated a preference for pseudonyms and suggested that he had been portrayed in a less

caring light than he felt was actually the case, so I decided to attempt the revisions myself.

15 October 2008

I just went through Ben's story and changed the names and dropped [material excised]. I really can't see what else to take out. So much of what he might feel damns him came from his own mouth. I think I'll send it like this and hope that on second reading, with the pseudonyms, he sees it differently and lets it through...

On further reflection, I've decided to delete his comment about how he was able to go with the flow in dealing with the baby and found it hard to empathise with Lynne finding new motherhood so stressful. I'll jump straight to the move to Forster and how it made family life less pressured because he could spend more time at home.

I dispatched the revised story with a brief email indicating the changes I had made and another copy of the release form. The alterations were minimal, but Ben replied that this one was 'not so raw' and said he now felt comfortable using real names. We exchanged a few more messages about minor edits and had just got to the point where Ben was about to sign the release, when he forwarded me a long email from one of Lynne's friends (whom I will call Anna) in which she expressed distress at how Lynne was depicted in the story. As I note in my diary, I put a lot of thought into my response.

28 October 2008

I was tempted to reply directly to Anna, pointing out how Ben's version is undercut if you read between the lines and take into account my slightly oppositional viewpoint as narrator, but I didn't because I think the policy I've adopted of dealing with 'others' through the principal carer is the most straightforward way of making sure that I don't talk behind my participant's back and cause upset by inadvertently (or deliberately) undermining them. It took a couple of hours to compose this reply for Ben. I hope it smoothes away any misgivings he may have felt after reading Anna's email. I tried to write it as sincerely as I could whilst respecting Anna's undoubted sincerity. I do believe the story is OK as it is.

Dear Ben,

Anna's email is eloquent and sincere and taps into some important issues. I don't know which version of the story you sent her – perhaps it was the original, raw one which has since been softened slightly? As I've mentioned before, I've shown various incarnations of it to friends and colleagues and one thing I have noticed is that they all read it differently. Some thought I was hard on you; some thought I was hard on Lynne; others praised me for being even-handed and non-intrusive! I think the combination of domestic politics and tragedy has a strong polarising effect on people's feelings about the characters and the situation. People bring a lot of their own personal baggage to the reading of a piece like this.

Of course you will decide for yourself how to respond to Anna but here are my thoughts about what she says:

She is not entirely right in suggesting that Lynne's voice is absent, except insofar as it's filtered through you. As the person listening to your account, I do try to include details (like the travel experiences that Lynne relished, the loss of her financial independence, the long lonely days in Thornleigh as a first-time mother) that establish Lynne as a person in her own right, someone the reader can understand and feel empathy for. I totally agree with everything that Anna says about how hard it is for young mums at home with small children – I certainly have not forgotten my experiences of that! In fact I felt so strongly that Lynne was caught up in an age-old situation that I step into the story and explicitly state that as you were talking to me I felt sad for her and it reminded me of how Betty Friedan spoke of the emptiness at the heart of the all-consuming housewife/mother role.

Regarding whether it is fair for the children to read about the failings of their mother – I think the story presents 'failings' on both sides and that is unequivocally what it should do, otherwise it would be a pointless, truthless piece of writing of no use to anybody. Perhaps it would be better for the children not to see it until they are old enough to realise that all

human beings are flawed and they struggle with situations sometimes. I think that once Chloe is a mother herself she will have no difficulty understanding that although you can love your children intensely, there is an inner core of yourself that you need to keep nourished as well. The part in the story that perhaps comes closest to making a criticism of Lynne is where I am dumbfounded that she didn't grab the opportunity to revitalise herself properly, to fill her own bucket, as Petrea would say. That 'guilt' Anna speaks of that stopped Lynne from ever putting her own needs first is terribly destructive.

You probably remember that in one of our email exchanges that we both agreed with the point Anna makes, that as the kids got older and became less dependent, the rocky patches in your relationship with Lynne would have become smoother. The tragedy is that Lynne was robbed of time for that to happen. But in the 'redemptive' note at the end, where she is shown as strong and courageous in the face of death and the last scene is of you doing such a good job of being a single dad, I think the likelihood of that occurring is underlined.¹⁰

love,

Janene

P.S. what a wonderful true friend Anna is, to write you such a letter

After two weeks of silence I emailed Ben asking how things stood with Anna and raising, yet again, the issue of the release form. He replied that Anna had responded: 'I'm glad you sent me Janene's comments from her friends and colleagues. It just reiterated that we can all read the same words, but take a different meaning'. He said he had signed the release form and had elected to have real names. All up, negotiations over 'Three steps behind' had taken three months, from the 7th of August, when I nervously dispatched the first draft, until the 3rd of November, when I gratefully received the release form in the post. It had been a long, hard slog for both of us, but we had managed to stay on amicable terms throughout. I believe that Ben really did accept the story as my

¹⁰ Some of the thoughts expressed in this email appear in the introduction to 'Three steps behind'

honest interpretation of the information he had shared with me, but still felt confused and ambivalent about his relationship with Lynne and did not entirely agree with my portrayal of it. Months later, he emailed me lengthy excerpts from a book he had just read that he felt cast more light on the origins of Lynne's difficulties with motherhood. I responded in a chatty, friendly fashion but did not engage with the material he had sent. By that point, I saw the story as finished.

The second instance of divergence arising between how a participant wanted their story told and other possible interpretations of it followed quite a different course. Maxine wished to speak about Gerard's peaceful Buddhist home death to counter the conception of dying as a fearful, miserable affair that all involved must cope with as best they can. She was at her most eloquent when discussing how serenely he accepted his diagnosis and in describing the events after his death, when friends, family and a group of fortuitously visiting monks gathered to give him a full Buddhist farewell. I agreed wholeheartedly that these parts of the story made it fascinating and distinctive, but I still needed the "middle bit", the actual details of caregiving. Specifics proved difficult to extract from Maxine, so I asked if she minded me speaking to some of the friends who had stepped forward to help with the caregiving while she was still working full-time. It was then I discovered, as Malcolm puts it, the critical thoughts 'burning in the minds of contemporaries' which the arrival of a biographer can call forth (1995, p. 12). When I began talking to people outside the family, I found that among the wide circle of friends there were some who thought Maxine had neglected Gerard when he most needed her, because she had been so determined to maintain normal life for herself and the girls. These friends conceded that when he was first diagnosed, Gerard had also spoken of his desire not to let his illness disrupt family routines, but they felt that the policy remained in place for too long. At times, they told me, Maxine seemed dismissive of Gerard – even seemed to regard his dependency as a nuisance. A large hot water bottle burn on his stomach several days before his death was cited as an example of her "cavalier" attitude.

From our interviews, I had already formed the impression that the life-as-usual approach, which saw Gerard reliant on friends in Sydney for company during his treatment, and friends in Armidale for much of his caregiving, continued a pattern whereby Maxine and the girls comprised a close mother-and-

daughters unit living alongside a somewhat aloof father figure who was absorbed in his own concerns. Through accretion of details, rather than explicit statements, I sought to include the nuance that Maxine may have felt detached or distant from Gerard at various points. But I decided to treat as gossip the accusation that she had been neglectful of him. I did not speak to her about it, nor mention it in the story, because I thought she would find the idea unfair and upsetting. Also, I added only a passing reference to the hot water bottle burn. As someone who had almost dropped her own utterly dependent mother on the floor, I knew a careless mistake did not imply a careless attitude. Maxine signed the release form after requesting only minor alterations to successive versions of the story.

The final example of a potentially fraught situation that I would like to explore in this section relates to consulting with my family about my own caregiving story. On the face of it, this seems like quite a different situation – after all, I was writing my own life, from my own perspective, using my own memories. Why should I need to check my interpretations with anyone else? But of course the situation is not really all that different. As Paul John Eakin points out, ‘Because our own lives never stand free of the lives of others, we are faced with our responsibility to those others whenever we write about ourselves’ (1999, p. 159). People I care about, people I have ongoing relationships with, play a crucial role in my memoir. In writing about them, I faced the same risks, of misrepresenting, hurting or betraying them, as I faced in writing the lives of my research participants.

When I first began thinking about doing a creative writing PhD on home-based palliative care, drawing on my family’s experiences, I ran the idea past my father Peter, my brother Michael, and Mum’s sisters Caroline and Kathy, to see if they objected. I knew they would all feature in my text, which would, as a family memoir, be ‘necessarily relational, plural rather than singular in focus... [oscillating] between biography and autobiography’ (Couser 2004, p. 56). To indicate the form it might take, I sent them my preliminary research proposal incorporating a creative nonfiction piece based on my visits to Brooklet in March and June of 2006. In the accompanying email, I wrote: ‘It’s too early to say if the final work will include anything looking at all like this, but I thought I ought to let close family know about it, that way you can tell me early on if you have any concerns’. They didn’t. They liked the idea of a book that would commemorate

Pat's life, and they were pleased that I planned to show it to them before it was published.

It wasn't until I sent my aunts and my brother an early draft of the memoir, and found that Kathy's first question was 'the agenda – was it meant to be about the patients or the people looking after them?' – that I realised I had misled them with my careless references to 'Mum's story'. Not surprisingly, they had expected to read Pat's story, the hero's journey, depicting her struggling defiantly against the odds. In fact, it was my story of how difficult I found it to watch and help as she deteriorated. Not the same thing at all, and possibly not what they had been hoping for.

They expressed a number of reservations, the chief one being that I needed to consider the fact that my father would read it. They agreed that as the story progressed I acknowledged his efforts to behave in a more caring manner, but they thought he might not get past the first page. Or indeed, the first two paragraphs:

In May 2006, my father Peter decided his wife's incontinence, vagueness and precarious sense of balance had become too much for him to handle. Anyone who needed this much tending must surely be at death's door. He rang me and said he had just put her into the palliative care unit at St Vincent's Hospital in Lismore.

'You what?' I spluttered. I had doubted his capacity to care for a person with advanced cancer, but I'd never imagined he would surrender the role so abruptly, with no warning. His own health was not an issue: he was superbly fit for a man approaching seventy. The trouble is, I thought, he's been a selfish, bad-tempered bastard all his life and can't become kind, considerate and self-sacrificing just because we need him to.

I had told my family that I would seriously consider all comments, but wouldn't necessarily act on them – unlike Annie Dillard, who famously promised her family that she would remove from her autobiography 'anything that anyone objects to – anything at all' (Dillard 1987, p. 70). In successive drafts of the story I worked at showing that there was love between my parents as well as anger and mistrust; and at bringing out the idea that my father was gradually changing for the better; but I was adamant that the 'selfish, bad-tempered bastard' line had to

stay. It was intended to be scathing and provocative, and it did accurately reflect how I had felt at the time. The problem was that the memoir ended with my mother's death, and my relationship with my father had improved since then. Paradoxically, this made it even more difficult to show him what I had written, as the following exchange of emails with a friend explains:

- > Have you shown the manuscript to your father yet? – you do soften him
- > around the edges just a very little at the end – the roses etc – but it's
- > fairly uncompromising and no doubt a very honest statement of your
- > feelings. I somehow wanted it to resolve a little more – some hint of
- > reconciliation and softness in the relationship between you and him. I know
- > that's probably fiction and not fact!! However it would be nice if it were true
- > – for him and for you.

Oh, I've had such torment over Dad's possible reaction! No, he hasn't seen it. I spent some time planning how to show it to him – considering whether it should be when he was here, or when we were at his place, so he wouldn't be alone when he read it, in case he was very distressed by my criticism. The thing is – he changed so much after Mum died – became pleased to see us, became far less grumpy, started getting out into the community and helping others – he's joined the Lions club and a landcare group and gone to computer classes for seniors. All these things that Mum would have LOVED him to do while she was alive. Of course, some of that is because he suddenly found himself terribly alone and friendless. But I'm not sure how much insight he has into how he was affecting others before then – not much I suspect – so reading this could come as a huge shock. Alternatively, he might understand himself better than I give him credit for, but still abhor the idea that I would expose him in public in this manner. Someone once said that it is a dreadful curse to have a writer in the family – someone throwing open the front door to let the world peer in.

I asked my brother what he thought and he said the best thing to do would be to tell Dad that I've finished drafting the story and have been showing it to people to get feedback, and only give it to him if he asked to see it. So that is what I have done, and he hasn't asked to see it. Quite apart from my criticisms (which he may or may not expect) I think he knows he would find it unbearable to read because he is still missing Mum so badly. In fact, he has surprised us all with the intensity of his grief. So as you see, it is very complicated.

I deliberately tried to be fair to him – to not portray Mum as a saint and him as a villain, to highlight the efforts he was making in the early days in terms of housework and meals, as well as mentioning the flowers and the crystal angel too. But I can't see how I can soften it – not without leaping forward into the future and saying something about his response to Mum's death. And I'm not sure how I'd do that, given that I'm writing in present tense and I really want it to end where it does (pers. comm. 17/5/2009).

As I wrote this thinking-out-loud email, it occurred to me that there was another softening element I could add to the story, if I would allow myself the liberty of collapsing time slightly. The day before Mum died, Dad told me it

made him feel like a ghoul, coming to sit by her bedside every day. I explained how important it was: somebody needed to be with her in case she had a seizure, she would have hated being left to die alone, and his presence allowed those of us who were staying at the nursing home overnight to have some respite. Two days after Mum died, I praised him for his contribution to the vigil:

16 November 2006

I told him how proud I was that he'd been able to do the day shifts, I said once I'd never have believed he was capable of it. He said he'd mellowed with age.

In the spirit of serving the larger, if not the literal, truth, I moved the second conversation back in time and joined it to the earlier one. Then I realised I could make the impact even stronger by copying Helen Garner's strategy in *The Spare Room*, where she uses a flash forward to jump beyond the focal three weeks of caregiving in order to explain what happened to Nicola, the dying friend. Her five pages of extra narration bristle with prefatory phrases such as: 'I didn't know that...', 'Nor could I foresee that...' and 'I had no idea that...'. My extension was much shorter and simpler. After Dad's line – 'I guess I'm mellowing with age' – I go on to say, on p.135:

Perhaps he is. Certainly, I will continue to be amazed by the changes in him in the months and years ahead. After Mum's death, he will surprise us all with the intensity of his grief. He will assuage his loneliness by reaching out to people with acts of kindness and consideration; he will curb his irritability and improve his relationships; he will become someone who remembers birthdays, someone who gives his time to community service organisations. After Mum's death, he will become someone who is much easier to love.

Hopefully, this succeeds in providing a kinder, more loving resolution for everybody, readers and father alike.

Emotional impact

Another question repeatedly put to me over the course of the project was whether I found it emotionally harrowing to be spending so much time absorbed in chronicles of suffering and death? In reply, I would point to the uplifting elements interwoven throughout the stories, such as love, joy, grace, courage and humour, while admitting that some of them were easier to write than others. Completing my own narrative was by far the most taxing, as I will discuss below. However, each seemed to enfold me in a particular atmosphere, one which reflected, in a diffuse and partial fashion, how I perceived its main characters: quirky individuality in Katherine's; vagueness in Maxine's; ambivalence and confusion in Ben's; doggedness in Kaye's; calm confidence in Rebecca's.

Initially, I worried about how I might respond to people who became upset while I was interviewing them. What if I empathised so excessively that I ended up wailing with them? It didn't happen, though I did get misty-eyed occasionally, and so did they. There were times when it was difficult to stay at my desk, but mostly this was unrelated to the topic. Transcribing is a tedious chore, regardless of the subject matter, and beginning a complex piece of writing is daunting for anybody: both are liable to stimulate a procrastinatory response. But once I was immersed in the work, the practical challenges of fashioning an engaging story from the material were uppermost in my mind, and I experienced all the usual feelings of excitement, frustration, anxiety, pleasure and satisfaction that attend any writing task. Although I was producing stories that many readers later told me moved them to tears, I wasn't crying as I typed.

However, getting started on writing my own caregiving memoir was undeniably gruelling. The printed version of my 2006 diary is more than 200 pages long; the daily entries range from 300 to 1600 words. I approached the task of reloading all these memories with a great deal of reluctance. There were some dense sections that I could not bring myself to read the first time through: I simply ran a highlighter down the side of the page to indicate that the content was relevant. When I shared my sense of dread with my husband, he urged me to abandon the project. 'Oh, don't do it. You don't have to do it,' he said. This was oddly helpful, because I immediately recognised that giving up was not an

option. Other people had dredged their memories so that I could write about their experiences; surely I could find the courage to do the same?

I began writing, making very slow progress at first, struggling to set down a few hundred words each day. Rumbblings of dyspepsia and a tense stiffness in my shoulders signalled how stressed I was feeling. My grief, my sense of loss, my memories of Mum's pitiable deterioration, had faded in the two years since her death. Renewing my awareness of what I, and she, had gone through felt like reliving it. Gradually, there were more days where the writing itself focused my energies and I felt happy with what I was producing, and fewer days where I recorded my mood as 'despondent', 'depressed' or 'dispirited'. Nonetheless, having a break midway was not a good idea, as this diary entry shows:

20 March 2009

It is as hard as I thought it would be to get back into the story after all these days off. Last weekend I'd planned to scrap everything I'd written on Friday and replace it with reflections about nursing homes, but now I feel unable to make editing decisions and I'm flipping through the diary printouts, enfeebled by a sense of sadness. I've slipped out of my brisk crafting-the-material persona and am back to worrying that if it is so painful to write, who on earth would want to read it?

It took me two months to finish the first draft, and another six weeks to revise it. I received detailed, constructive feedback from family, friends and supervisors, but quickly learnt that family members could not be expected to leap straight from an initial reading into a critique of the memoir's adequacy. Seeing my husband Chris unable to respond to my query about what he thought of it because he was crying so much; and listening to Caroline repeatedly saying she was unable to take much in on the first reading because it was so upsetting, made me realise that when I gave it to people who had been closely involved, their emotional responses would parallel those I had experienced as I was preparing to write: the ache of remembering, of opening wounds afresh, of feeling shocked and horrified and grief-stricken.

Although I have highlighted the most distressing aspects of writing the memoir, I do believe the overall impact on me was positive, not negative. The

therapeutic benefits of storytelling are recognised in both the humanities and the scientific literature (Grinyer 2006; Wright & Cheung Chung 2001). Writing a story of trauma, loss or tragedy, or telling it to an attentive listener, is almost always experienced as a cathartic and clarifying act, despite the pain that may be involved (Dyregrov 2004; Grinyer 2004). In writing my diary, I had set down the events and my reactions to them in daily fragments; writing the memoir forced me to take my half-digested sorrow and pain and process it properly. It brought structure to the whole, and helped me understand and accept what had happened. The memoir also gave me the opportunity to look at who I was, and to consider whether I wanted to perpetuate certain patterns, such as thinking of myself as incorrigibly shy, which had begun in childhood and carried over to adult life. Turning my memories into a coherent textual object also gave me license to set them to one side, as Merril Joan Gerber articulates in this passage from *Gut Feelings: A writer's truths and minute inventions*:

While most people live the experiences of their lives and move on, writers (maybe not all, but those whose base of material is autobiography) seem to have a compulsion to live at least twice. I learned the effects of this in the year my father died suddenly, and very young, of leukemia. Until I wrote my first novel, *An Antique Man*, which is based on his death, I was unable to stop reliving in my mind every moment of his suffering and rapid decline. Once I captured this in its full dimensions on paper, I felt enormous relief that nothing of his ending would be forgotten, that all he endured (and we, his family, endured) was safe and available to me and no longer needed to run like an endless movie through my mind. Beyond that, I hoped I had made something more of it, a story for others to read (2003, pp. xi-xii).

Lingering doubts about the value of foisting yet another misery memoir on the world were assuaged by these comments from Rebecca, who had asked if she could read it:

I am not sure whether it is because so much of it resonates or because it just is so wonderfully written, but I cried from page 12 to the end. Your writing evokes strong emotions and you are not scared to be critical of your inner thoughts – this is very powerful because it allows all of us who have struggled with the dying process to understand our frustrations, negativity and anger at our parents for their frailty as part of the process. So I am very grateful to you for being brave enough to voice them... [It is] really just our human experience in words – certainly I went through the same things and you give solace and release at the same time with your writing. I couldn't think of a criticism at all – beautiful words, Janene, thank you for sharing this (Rebecca, pers. comm. 15/5/2009).

I did not ask my participants how being involved in my research project had affected them, but several did spontaneously offer their views on either the

process or the outcome. Kaye, who typed twenty pages of information for me one-handedly while she was at home from TAFE after breaking her shoulder in a fall, commented: ‘Doing this exercise has been interesting because it has made me aware of just how much John suffered and how relieved I am he is at peace’ (Kaye, pers. comm. 11/1/2008). Rebecca responded to the first draft of ‘I just cannot’ by saying that she was ‘absolutely amazed and awed by this story, which is so my story’ (Rebecca, pers. comm. 16/1/2009). Katherine, who told me that she had felt ‘dread’ when she first contemplated participating in the research, ended up by saying it had been a pleasure:

I am very happy with what you have done. I cannot imagine the hours you have put in to complete the document. I am happy with the content, the way you have handled the topic and the manner in which you have kept me up to date with the various rewritings.

It is a wonderful document for the family to have. I think that you write superbly and thank you for being very easy to deal with (Katherine, pers. comm. 16/4/2008).

However, I should note that Katherine was a rather volatile participant, and at various times evinced extreme anxiety at the prospect of the story being published. She wanted to know whether signing the release form meant that the writing would become my sole property. Could I change anything that had been written without her permission? (I assured her that although I might continue to tinker with the story, I didn’t envisage any major changes; and reiterated my willingness to send advance copies of anything slated for publication). She vacillated between the choice of real names and false names, finally becoming the only participant to opt for the latter. When ‘Retreat to the castle’ was shortlisted for the 2010 Calibre Prize, and was published in *Australian Book Review*, Katherine congratulated me heartily but said she would tell anyone who claimed to have recognised her in the story that it was creative nonfiction, and was my interpretation of someone who did sound rather like her husband. I was surprised by her persistent unwillingness to be identified with the story, given that she was most complimentary about my writing and had assured me that I had ‘captured in words the man that was my husband’. The explanation, when we eventually did talk about her concerns, turned out to be quite simple. She knew that the friends mentioned in the first few pages – the ones who had stayed too long, talked too much and proffered too much advice – would all recognise

themselves, and she didn't want to alienate them. Fortunately, we had acquaintances in common and I was able to reassure her that those who had spoken to me had seemed moved rather than offended by the story. One, who told me she had decided not to mention to Katherine that she had read the story in order to 'give her some space', commented: 'I've been friends with her for forty years and it was like listening to her speak.'

Journalistic practice

In June 2009, at a point where the manuscript for 'A Hospital Bed at Home' was complete but my exegesis existed only in the form of several conference papers, a journal article, notes on books I'd read, and diary entries, I began working two days a week as a print journalist with *The Armidale Express*. I had no formal qualifications but I did have interviewing experience, a list of publications and well-established links within the local community, all of which proved sufficient to land a position at a tri-weekly regional newspaper.

Some media outlets prohibit staff from showing stories to subjects before they are published (Harrington 2007) because it is regarded as a risky, unnecessary, time-wasting exercise that might compromise the quality of the reporting and the independence of the publication. However, at the *Express* emailing drafts to subjects is seen as acceptable practice, occasionally, for fact-checking purposes. The absence of an outright prohibition has allowed me to (discreetly and partially) carry over into my work as a journalist the consultative style that I adopted for my thesis. If I am writing a profile or a feature story about a particular person, I will usually offer to email them a draft so that they can point out errors or inadvertent misinterpretations. I do not promise to remove or alter everything (or anything) that they object to, but I do let them know I am open to discussing changes.

Unsurprisingly, I have found that my interviewees appreciate being given the opportunity to review a pre-publication version of the story. Often I can incorporate the amendments they suggest; sometimes I have to explain that the proposed change to a quotation will make it sound overly formal, or that the extra sentence thanking a long list of people will push the story over its word

limit. It would be beyond the scope of this thesis to present and analyse specific cases and outcomes here,¹¹ but I can say that with some notable exceptions most people negotiate in good faith and with good grace, and do not try to take advantage of my offer. Sometimes the story is improved because an error of fact or nuance is corrected; sometimes the change makes no discernable difference to the quality of the story but is important to the person concerned. In such cases, I believe that accommodating their preferences is simply a respectful, relationship-enhancing way to behave.

I accept that this consultative style of working is impractical for news stories with tight deadlines and inappropriate for stories where a confrontational approach is required. That said, I think it is generally well-suited to a non-daily paper that reports on the activities and achievements of a small community of people. More often than not, stories have a reasonable lead time and are celebratory rather than accusatory; also, there is a high probability that the journalist will encounter the subject again either professionally or socially, so operating in a manner that promotes trust and respect is a good long-term strategy. Recently, an interviewee told me that my willingness to let her see a draft of the story I had written about her career as a film maker, and the non-sensationalist way I had incorporated relevant but sensitive personal details, had restored her faith in journalists. Such feedback makes the small amount of extra effort involved in working consultatively truly worthwhile.

¹¹ I have been keeping notes about my experiences and would like to do further work in this area at a later date.

Chapter Five

CONCLUSION

The preceding chapters have placed my creative work within a contextual framework by discussing publications and praxis relating to both the topic and the process followed to produce the manuscript. Academic, instructional and auto/biographical literature about caring for a terminally-ill family member, together with personal experience, informed the understanding of home-based palliative care that I brought to the researching and writing of my creative nonfiction stories. Literature from the fields of interpretivist qualitative methodology, narrative inquiry, creative nonfiction and life writing ethics shaped my decisions about how to conduct the project and how to behave in relation to my participants. Full details of how I recruited participants, gathered materials, and created the stories in a consultative manner, together with examples of how negotiations were handled when conflict arose, have been presented.

This concluding chapter discusses the dual significance of my thesis: as a creative work based on narrative inquiry into the important topic of home-based palliative care; and as a methodological contribution to the debate about striking a balance between the interpretive authority of a creative nonfiction writer and the ethical treatment of a research participant, particularly in situations involving sensitive emotional territory.

Topical significance

The impetus for embarking on this project came from intense personal experience that left me feeling impelled to explore, through writing, the ways in which people cope with the challenge of caring for a loved one who is dying at home. My mother spent her final six months in a state of utter dependence, unable to communicate effectively, stand up, feed herself or even roll over in bed without assistance. Like those who contributed to the national inquiry into the social impact of caring for terminally ill people, our family found the physical, emotional and psychological demands of caregiving to be ‘the hardest thing we

have ever done' (Palliative Care Australia 2004). People living in a rural or regional area, as we were, face additional disadvantages due to the paucity of local services and the logistical difficulties of travelling to access specialist advice and treatment. All family carers, but particularly non-metropolitan ones, 'make do' with whatever they can wrangle from the system (Palliative Care Australia 2004), and can be justifiably proud of how well they fulfill their role and express their love by providing care 'in the face of minimal information, limited service provision, and no previous experience' (Grbich, Parker & Maddocks 2001, p. 35).

Although our culture is often categorised as youth-obsessed and death-denying, as the baby boomers enter their sixth and seventh decades and begin confronting their mortality, and also dealing with the mortal illnesses of their parents and friends, there has been a surge in the market for literature depicting what happens as the end of life approaches (Wyndham 2008a). Death and dying emerged as the unofficial theme of the Sydney Writers' Festival in 2008, with director Wendy Were stating she had been 'astonished to discover just how many books were being published at this moment on the subject' (Bennie 2008). The list for that year included: *The Household Guide to Dying* (Adelaide 2008); *The Spare Room* (Garner 2008); *Swimming in a Sea of Death* (Rieff 2008); *The Young Widow's Book of Home Improvement* (Lloyd 2008); *Life in his Hands* (Wyndham 2008b); *The Book of Dead Philosophers* (Critchley 2008) and *Sweet Sorrow: A beginner's guide to death* (Wakely 2008). Visual representations of the topic have also been provoking discussion, with Annie Leibovitz controversially publishing and exhibiting intimate photographs she had taken of Susan Sontag immediately before and after she died, and the National Portrait Gallery in Canberra mounting *Reveries: Photography and Mortality*, containing images of the dead and dying (2007). The curator of *Reveries*, Helen Ennis, interviewed by Wakely for *Sweet Sorrow*, said she believed such an exhibition would have been unacceptable five years ago, and its success indicated that 'perhaps baby boomers, who had engaged with and reflected critically about all manner of issues throughout their lives...were now ready to rethink their attitude to death and dying' (Wakely 2008, p. 49). Wider engagement with this formerly taboo subject is unlikely to be a transient phenomenon; the ageing of the Australian population is projected to cause the annual number of deaths to double

within the next forty years (Australian Bureau of Statistics 2009). As the majority (at least three-quarters) of these people will die “anticipated deaths” from chronic conditions such as cancer or heart disease, there will be a concomitant rise in the demand for both institutional and home-based palliative care (Palliative Care Australia 2010).

In such an environment, a collection of moving and enlightening creative nonfiction stories about Australian experiences of tending a loved one at home during the final stages of a terminal illness is likely to find a market. Three excerpts from ‘A Hospital Bed at Home’ have already been published: ‘Coping’, a section of my memoir, appeared in the anthology *Re-Placement* (Carey 2008) and was one of several pieces singled out for favourable mention by *Sydney Morning Herald* reviewer Kerryn Goldsworthy (2009); ‘Retreat to the castle’ was published in *Australian Book Review* (Carey 2010a) after being shortlisted for the 2010 Calibre Prize for an outstanding essay; and ‘Excerpt and Research Statement: A Hospital Bed at Home’, containing a 3,000 word section of ‘Three steps behind’, was published in a special issue of the ‘A’ ranked writing journal *TEXT* (Carey 2010b), which was dedicated to examining creative writing as research .

Methodological significance

As storytelling animals, humans have a natural tendency to find narratives of lived experience an appealing way to make sense of complex phenomena, and the “narrative turn” within academia attests to the power of stories to convey truths about human existence (Novak 1975; Polkinghorne 1988). Narrative inquiry is increasingly being joined to creative practice to deliver research findings in evocative artistic forms (Richardson 2000). This serves to produce engaging representations offering not generalisable knowledge claims but rather an expanded sense of the topic and its complexities (Clandinin & Connelly 2000). Such artistic representations entice audiences to connect and empathise with situations and characters (Barone 2008) and acknowledge the researcher as ‘a situated subjectivity engaged in knowing and telling’ (Richardson 2000, p. 931).

This realm of research-based creative practice is where my project is located. Specifically, it is a biographical type of life writing within the field of narrative inquiry, with an investigation of lived experience culminating in creative nonfiction stories as a research outcome. However, using lives as fodder for writing can be an ethically fraught undertaking, as debates within the fields of auto/biography, narrative inquiry and journalism demonstrate. Conflicting loyalties and competing values create moral quandaries for life writers. On the one hand, examples abound of life writing causing harm by deliberately or inadvertently impinging upon the subject's privacy, reputation, or sense of self (Couser 2004; Donaldson, Read & Walter 1992; Eakin 1999). On the other hand, biographers, scholars and journalists rightly position interpretive independence as life writers' principal bulwark against hagiography, superficiality and dishonesty (Bloom 2003; Chase 1996; Pybus 2000). According to Janet Malcolm, the result is a moral impasse: betrayal is the inevitable canker at the heart of the writer-subject relationship, because after trust is won and confidences are imparted, the 'text's necessities' must take precedence over the subject's feelings (Malcolm 2004, p. 163).

The struggle to find a workable balance between the exigencies of interpretive authority and the exigencies of ethical responsibility became my research problem, as I sought to take a non-exploitative, non-maleficent approach to the task of producing non-superficial, non-rose-tinted, nuanced accounts of home-based palliative caregiving. The highly consultative process I eventually adopted was the result of a number of factors, including the emotionally sensitive nature of the topic, the rigorous standards upheld by the human research ethics committee of Hunter New England Health, and the serendipitous discovery early during the project that the threatened withdrawal of a valued participant could be averted, and her trust in me enhanced, by sharing my draft attempts at writing the narrative based on her experiences. My own inclination was also a factor, as I brought to the project a longstanding attachment to qualitative research methodology, particularly the type that promotes an empathic understanding of another's worldview and assumes that meaningful reality is co-constructed as human beings engage with each other within physical, social, cultural and historical contexts (Crotty 1998; Neuman 2000).

Rather than corroding my writerly integrity, I found that the iterative cycle of gathering information, drafting the narrative, seeking feedback, and negotiating disagreements led to revisions and extensions of the stories that made them infinitely richer. Such an outcome is not without precedent. In ‘A phantom at my shoulder: The final draft of *Charles Perkins: A Biography*’, author Peter Read writes positively about the intensive feedback he received from Aboriginal activist and senior public servant Charles Perkins, concluding that it enlarged his understanding of a man he had just spent three years studying and resulted in the text becoming more subtle and multi-layered than it had been previously (Read 1992). Perkins made numerous comments, suggestions and corrections in the margins of the draft manuscript, which the pair worked through together, page by page, amicably and fruitfully:

Contrary to what one might have expected, the process at no time was one of brow-beating or arguments over author’s versus subject’s rights. The sessions were co-operative and unexpectedly creative, as our interviews had been (Read 1992, p. 159).

The effect of the changes was to introduce subtle inconsistencies in Perkins’s stated attitudes to certain key events and people; to disrupt the presentation of singular, coherent meanings that Read, as biographer, had unconsciously sought to distil. The eleventh-hour additions reflect, argues Read, ‘unresolvable, multivariant interpretations’ co-existing in Perkins’s mind. Abstaining from an artificial synthesis and allowing the reader to comprehend the biographical subject from reports of their words and actions is ‘a methodology sympathetic to the subject’s own self-perceptions’ and is congruent with how people develop an intuitive understanding of others in everyday life (Read 1992, pp. 169-70).

Like Peter Read, I discovered that working on a draft manuscript with the person being written about was an unexpectedly creative process, and one that promoted a more nuanced understanding. The outcomes of the consultative approach are manifest in the product – the manuscript ‘A Hospital Bed at Home’ – and in the exegetical presentation of the process that was followed and the decisions that were made. Taken as a whole, I believe my thesis demonstrates that it is possible to tell a story about someone’s life in a way that strives to be ethically responsible, while at the same time telling it in a way that produces

vivid, rich and truthful creative nonfiction animated by the author's personal voice.

I must admit, however, that the nature of my stories – with information coming principally from one source, involving a testimonial about felt experience and pertaining to sensitive emotional territory – is one where the process of negotiation is eased by the sheer inappropriateness of being overtly critical of the person being depicted. Sometimes those who pin lives to the page – scholars, biographers, journalists, creative nonfiction writers – must go beyond, or call into question, the informant's point of view, in order to exercise interpretive authority. Journalists in particular may need to adopt a sceptical or even adversarial attitude towards their sources. There are no generic solutions to the moral dilemmas inherent in life writing. I am well aware that, as Janet Malcolm states, often 'the best [we] can do... is still not good enough' (Malcolm 2004, p. 163). Nonetheless, I hope that I have come close to achieving my goal of presenting stories about real people dealing with an extraordinarily challenging situation, and bringing to it the full range of characteristically human strengths and weaknesses, without hurting, embarrassing or misrepresenting those who so generously agreed to speak with me.

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APPENDIX 1

CAREGIVING RESEARCH

Invitation to Participate

Do you know what it is like to care for a person living at home who has a life-threatening illness?

Would you like to help increase community understanding about the challenges faced by family caregivers?

I am looking for people who will write an account of their thoughts, feelings and anecdotes about their experience as a family carer, and talk to me about what they write.

Based on this research, and drawing on my reflections as a carer for my own mother, I will be writing a book of non-fiction stories as part of my PhD. If published, I hope that this book, “A Hospital Bed At Home: Stories of palliative caregiving by Australian families”, will be a useful resource for carers, health professionals and policy makers.

To find out more about this research, please mail me your contact details using the Expression of Interest tear-off form overleaf, or contact me directly. I will then send you a full information package.

Janene Carey Ph: (02) 6775 1913

Email: s0158025@student.cqu.edu.au

Expression of Interest

My name is: _____

I am interested in receiving more information about the research project.

Please phone me on: _____

OR

Please mail a set of research documents to this address:

Please post the tear-off section to:

Ms. Janene Carey,
5 Highlands Rd
Armidale
NSW 2350

APPENDIX 2

Information Sheet for Carers

Information Statement for Carers about the Research Project:

“A Hospital Bed at Home: Stories of palliative caregiving by Australian families”

Version 5.0 Dated 4/03/08

You are invited to take part in the research project identified above. My name is Janene Carey and I am conducting this research as part of my PhD studies at Central Queensland University, under the supervision of Associate Professor Donna Lee Brien, School of Arts and Creative Enterprise (CQU) and Dr. Glenda Parmenter, School of Health (UNE).

You are being invited to participate because you are, or have been, the primary caregiver for a person living at home receiving palliative care services.

Why is the research being done?

Many people with life-threatening illnesses are cared for at home. The purpose of my research project is to provide an in-depth look at the experience of at-home palliative caregiving. Based on what participants tell me I will be writing not just an academic thesis, but also a nonfiction book of stories intended for a general audience. If published, I hope that the book “A Hospital Bed At Home” will serve to increase community understanding and empathy about the challenges faced by family carers of people with life-threatening illnesses. I also hope it will be useful for other carers, health professionals and policy makers.

Who can participate in the research?

You may be a participant if you are, or have been, the primary caregiver for a person living at home receiving palliative care services. You must be eighteen years of age or older to participate. You will be asked to write down anecdotes,

thoughts and feelings about your life as a carer and to talk to me about your experiences.

If you are a current carer, the person you are looking after will need to give permission for you to tell me about their situation and for this information to be included in the research project.

Given the kind of research I am doing, I can only take about twenty participants and will be looking for carers from a range of backgrounds (for example, men and women, various age groups, people from rural, regional and urban locations). Unfortunately, I may not be able to include everyone who would like to be involved.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you, or anyone you may be caring for, in any way, and will not affect access to care services. If you do decide to participate, you may withdraw from the project at any time without giving a reason. You will also have the option of withdrawing the written and spoken information you have provided.

What would you be asked to do?

If you agree to participate, you will be asked to:

- Have an initial meeting with me where we talk about the background to your situation and discuss any questions or concerns you may have about the project. I will come to your house or if you prefer, we can meet somewhere else. This should take about one hour. With your permission, I would like to tape record our conversation so I do not forget important details. You can ask me to stop the recording at any time.
- Write an account of your time as a carer. This should include background information about how you came to be in this role, as well as recounting your personal experience as a carer. I will be looking for dramatic, touching,

funny, or sad incidents that illuminate an aspect of the experience of being a carer.

- Allow me to read what you have written. You can post it to me using a prepaid envelope supplied by me, or email it to me.
- Have a second meeting with me to talk in more depth about what you have written so that I understand what you mean and I can follow-up on things that look like good material for a story. This discussion should take about an hour and with your permission, it will be tape recorded. You may stop, edit and erase the tape at any time during this conversation.
- If necessary, do more writing, send it to me again, and have a third meeting similar to the second one.

What are the risks and benefits of participating?

Given the emotional nature of this topic, there is a possibility that thinking about these difficult circumstances may cause you to become anxious or upset. If needed, professional counselling services are available through the social workers at your local Community Health Service. Contact details are included at the end of this Information Sheet.

Whilst I can offer no guarantee that you will benefit personally from this research, I can say that some people in similar situations have reported that the opportunity to write, talk and think about their experiences was helpful and valuable.

How will your privacy be protected?

I will not give information about you or your family to anyone (except my supervisors) without your explicit consent.

With your consent, I will tape record our conversations and transcribe some or all sections of them. You will be given the opportunity to review the audio recordings and/or transcripts and edit or erase your contributions if you wish.

Copies of written material and audio tapes will be held securely in my office. Only people in the research team will have access to them. They will be destroyed five years after the date of my thesis submission.

How will the information collected be used?

I will use the information participants give me as a basis for writing creative nonfiction stories. Creative nonfiction is a form of writing that uses methods common to works of fiction, whilst keeping true to the real life events upon which the story is based. I hope that these stories will be published as a book.

The descriptive and detailed nature of the stories I will be writing make it difficult to promise that participants will be anonymous. I can disguise names, dates and locations, but cannot guarantee that someone who knows your family circumstances will not be able to recognise you in the stories.

I will use your information in the book manuscript and thesis for my PhD, for conference papers and for articles in scholarly journals. Prior to submission of the PhD, you will be offered drafts of writing based on your material and showing its usage in context. You will be invited to suggest modifications or request deletions before signing a Release form. If a mutually satisfactory version of the writing cannot be negotiated, you will be completely free to withdraw your contribution. If you want real names to appear with your material in the publication you will have to nominate this option on the Release form, otherwise pseudonyms will be used.

My PhD is due to be submitted by the end of February, 2011. After this time, you will be sent a letter detailing how you can access electronic copies of the final version of the thesis and the book manuscript.

You need to understand that I cannot promise that the book manuscript will be published. Nor can I promise that all the information that I collect will be included in the book or any other publication. Responsibility for the final form of the written products of this research rests with me and selection and reworking of material will be necessary. I will be identified as the author of any publications arising from the research and will have copyright of those publications.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact me or one of my supervisors.

If you would like to participate, please complete the attached Consent Form and return it to Janene Carey, 5 Highlands Rd, Armidale, NSW 2350. I will then contact you to arrange a time convenient to you for our first meeting.

Further information

Thank you for considering this invitation. We will be happy to answer any questions about this research.

Janene Carey Ph: 02 6775 1913 Email s0158025@student.cqu.edu.au

Donna Lee Brien Ph: 07 4923 2014 Email d.brien@cqu.edu.au

Glenda Parmenter Ph: 02 6773 3683 Email gparment@une.edu.au

Janene Carey	A/Prof Donna Lee Brien	Dr Glenda Parmenter
(PhD candidate)	(Supervisor)	(Co-supervisor)

Complaints about this research

This project has been approved by Central Queensland University Human Research Ethics Committee [Approval No. H08/02-014, valid to 31/12/2010] and the Hunter New England Human Research Ethics Committee of Hunter New England Health [Reference: 07/04/18/4.01, valid to 10/05/2010]

Should you have any complaints concerning the manner in which this research is conducted, please contact either:

Ethics and Compliance Officer Office of Research Central Queensland University Rockhampton, QLD 4702. Telephone: (07) 4923 2603 Email: Ethics@cqu.edu.au	Dr. Nicole Gerrand Professional Officer (Research Ethics) Hunter New England Human Research Ethics Committee Hunter New England Health, Locked Bag 1, New Lambton, NSW 2305. Telephone: (02) 4921 4950 Email: Nicole.Gerrand@hnehealth.nsw.gov.au
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Community Health Contact Details for Counselling Services

Armidale	6776 9600
Glen Innes	6739 0100
Guyra	6738 4000
Tamworth	6767 8100
Walcha	6774 2400
Newcastle	4925 7800

APPENDIX 3

Information Sheet for Patients

Information Statement for Patients about the Research Project:

“A Hospital Bed at Home: Stories of palliative caregiving by Australian families”

Patient Version 5.0 Dated 4/03/08

Your family carer has been invited to take part in the research project identified above. My name is Janene Carey and I am conducting this research as part of my PhD studies at Central Queensland University, under the supervision of Associate Professor Donna Lee Brien, School of Arts and Creative Enterprise (CQU) and Dr. Glenda Parmenter, School of Health (UNE).

Your carer has been invited to participate because he/she is the primary caregiver for you, a person living at home who is receiving palliative care services.

Why is the research being done?

Many people with life-threatening illnesses are cared for at home. The purpose of my research project is to provide an in-depth look at the experience of at-home palliative caregiving. Based on what participants tell me I will be writing not just an academic thesis, but also a nonfiction book of stories intended for a general audience. If published, I hope that the book “A Hospital Bed At Home” will serve to increase community understanding and empathy about the challenges faced by family carers of people with life-threatening illnesses. I also hope it will be useful for other carers, health professionals and policy makers.

Who can participate in the research?

People may participate if they are currently the primary caregiver for a person living at home who is receiving palliative care services. They will be asked to write down anecdotes, thoughts and feelings about their life as a carer and to talk to me about their experiences.

Your carer can only participate if you give permission for them to tell me about your situation and for this information to be included in the research project.

Given the kind of research I am doing, I can only take about twenty participants and will be looking for carers from a range of backgrounds (for example, men and women, various age groups, people from rural, regional and urban locations). Unfortunately, I may not be able to include everyone who would like to be involved.

What choice do you have?

Consenting to your carer's participation in this research is entirely your choice. Only patients and carers who give their informed consent will be included in the project. Whether you decide to give your permission or not, your decision will not disadvantage you or your carer in any way and will not affect your access to care services.

If you do decide to consent to your carer's participation, you may withdraw your consent at any time without giving a reason. You will also have the option of withdrawing written and spoken information relating to you.

What will your carer be asked to do?

If you consent to your carer's participation, he/she will be asked to:

- Have an initial meeting with me where we talk about the background to your situation and discuss any questions or concerns either of you may have about the project. I will come to your house or if preferred, we can meet somewhere else. This should take about one hour.
- Write an account about his/her experiences as a carer. This should include background information about how he/she came to be in this role, as well as recounting his/her personal experience as a carer. I will be looking for dramatic, touching, funny, or sad incidents that illuminate an aspect of the experience of being a carer.
- Allow me to read what he/she has written.
- Have a second meeting with me to talk in more depth about what he/she has written so that I understand what they mean, and I can follow-up on things

that look like good material for a story. This discussion should take about an hour.

- If necessary, do more writing, send it to me again, and have a third meeting similar to the second one.

What are the risks and benefits of participating?

Given the emotional nature of this topic, there is a possibility that thinking about the difficult circumstances confronting your family may cause your carer to become anxious or upset. If needed, professional counselling services are available through the social workers at your local Community Health Service.

Whilst I can offer no guarantee that anyone will benefit personally from this research, I can say that some people in similar situations have reported that the opportunity to write, talk and think about their experiences was helpful and valuable.

How will your privacy be protected?

I will not give information about you or your family to anyone (except my supervisors) without your explicit consent.

Copies of written material and audio tapes will be held securely in my office. Only people in the research team will have access to them. They will be destroyed five years after the date of my thesis submission.

How will the information collected be used?

I will use the information participants give me as a basis for writing creative nonfiction stories. Creative nonfiction is a form of writing that uses methods common to works of fiction, whilst keeping true to the real life events upon which the story is based. I hope that these stories will be published as a book.

The descriptive and detailed nature of the stories I will be writing make it difficult to promise that participants will be anonymous. I can disguise names, dates and locations but cannot guarantee that someone who knows your family circumstances will not be able to recognise your carer in the stories.

I will use participants' information in the book manuscript and thesis for my PhD, for conference papers and for articles in scholarly journals. Prior to submission of the PhD, each participant will be offered drafts of writing based on his/her material and showing its usage in context. They will be invited to suggest modifications or request deletions before signing a Release form. If a mutually satisfactory version of the writing cannot be negotiated, a participant will be completely free to withdraw his/her contribution. If participants want real names to appear with their material, they will have to nominate this option on the Release form, otherwise pseudonyms will be used.

My PhD is due to be submitted by the end of February, 2011. After this time, your carer will be sent a letter detailing how he/she can access electronic copies of the final version of the thesis and the book manuscript.

You need to understand that I cannot promise that the book manuscript will be published. Nor can I promise that all the information that I collect will be included in the book or any other publication. Responsibility for the final form of the written products of this research rests with me and selection and reworking of material will be necessary. I will be identified as the author of any publications arising from the research and will have copyright of those publications.

What do you need to do to consent?

Please read this Information Statement and be sure you understand its contents before you consent to your carer's participation. If there is anything you do not understand, or you have questions, contact me or one of my supervisors.

If you would like to consent to the participation of your carer, please complete the attached Consent Form and return it to Janene Carey, 5 Highlands Rd, Armidale NSW 2350.

Further information

We will be happy to answer any questions about this research.

Janene Carey Ph: 02 6775 1913 Email s0158025@student.cqu.edu.au

Donna Lee Brien Ph: 07 4923 2014 Email d.brien@cqu.edu.au

Glenda Parmenter Ph: 02 6773 3683 Email gparment@une.edu.au

Janene Carey	A/Prof Donna Lee Brien	Dr Glenda Parmenter
(PhD candidate)	(Supervisor)	(Co-supervisor)

Complaints about this research

This project has been approved by Central Queensland University Human Research Ethics Committee [Approval No. H08/02-014, valid to 31/12/2010] and the Hunter New England Human Research Ethics Committee of Hunter New England Health [Reference: 07/04/18/4.01, valid to 10/05/2010]

Should you have any complaints concerning the manner in which this research is conducted, please contact either:

Ethics and Compliance Officer Office of Research Central Queensland University Rockhampton, QLD 4702. Telephone: (07) 4923 2603 Email: Ethics@cqu.edu.au	Dr. Nicole Gerrand Professional Officer (Research Ethics) Hunter New England Human Research Ethics Committee Hunter New England Health, Locked Bag 1, New Lambton, NSW 2305. Telephone: (02) 4921 4950 Email: Nicole.Gerrand@hnehealth.nsw.gov.au
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APPENDIX 4

Consent Form for Carers

Consent Form for the Research Project: A Hospital Bed at Home

Version 4.0 Dated 4/03/08

Researchers: Janene Carey (doctoral candidate); A/Prof Donna Lee Brien, School of Arts and Creative Enterprise (CQU); Dr. Glenda Parmenter, School of Health (UNE).

I agree to participate in the above research project and give my consent freely. I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained. I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to:

Writing an account of my experiences as a carer, to be a starting point for discussions with the researcher Yes / No

Tape recording of discussions with the researcher Yes / No

Publications (e.g. conference papers, journal articles, books) based on the research data Yes / No

I understand that I will be given the opportunity to review audio recordings and/or transcripts of interviews and edit or erase my contributions. I understand that prior to PhD submission, I will be given the opportunity to review writing based on my material and request alterations. I understand that my personal information will remain confidential to the researchers. I have had the opportunity to have questions answered to my satisfaction.

I am 18 years of age or older.

Print Name: _____

Signature: _____

Date: _____

Contact Details

Janene Carey Ph: 02 6775 1913 Email s0158025@student.cqu.edu.au

Donna Lee Brien Ph: 07 4923 2014 Email d.brien@cqu.edu.au

Glenda Parmenter Ph: 02 6773 3683 Email gparment@une.edu.au

Please return this form to Janene Carey, 5 Highlands Rd, Armidale, NSW 2350

APPENDIX 5

Consent Form for Patients

Consent Form for the Research Project: A Hospital Bed at Home

Patient Version 4.0 Dated 4/03/08

Researchers: Janene Carey (doctoral candidate); A/Prof Donna Lee Brien, School of Arts and Creative Enterprise (CQU); Dr. Glenda Parmenter, School of Health (UNE).

I understand that my family carer wishes to be involved in the above research project and I do not object. I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained. I understand I can withdraw my consent from the project at any time and do not have to give any reason for withdrawing. If I withdraw my consent, my carer will not be able to participate.

I consent to:

Discussions between my carer and the researcher that may include details about me and my health situation Yes / No

Publications (e.g. conference papers, journal articles, books) based on the research data Yes / No

I understand that my personal information will remain confidential to the researchers. I have had the opportunity to have questions answered to my satisfaction.

Print Name: _____

Signature: _____

Date: _____

Contact Details

Janene Carey Ph: 02 6775 1913 Email s0158025@student.cqu.edu.au

Donna Lee Brien Ph: 07 4923 2014 Email d.brien@cqu.edu.au

Glenda Parmenter Ph: 02 6773 3683 Email gparment@une.edu.au

Please return this form to Janene Carey, 5 Highlands Rd, Armidale, NSW 2350

APPENDIX 6

Release Form

Release of Information Form: A Hospital Bed at Home

Version 2.0 Dated 31/08/08

As a participant in the research project, A Hospital Bed at Home, I was given the opportunity to read, discuss and amend draft versions of the narrative about my experiences.

I hereby release the information that I supplied for publication.

I stipulate that people featured in the narrative should have:

false names / real names

Name: _____

Signature: _____

Date: _____

Contact Details

Janene Carey Ph: 02 6775 1913 Email s0158025@student.cqu.edu.au

Donna Lee Brien Ph: 07 4923 2014 Email d.brien@cqu.edu.au

Glenda Parmenter Ph: 02 6773 3683 Email gparment@une.edu.au

Please return this form to Janene Carey, 5 Highlands Rd, Armidale, NSW 2350

