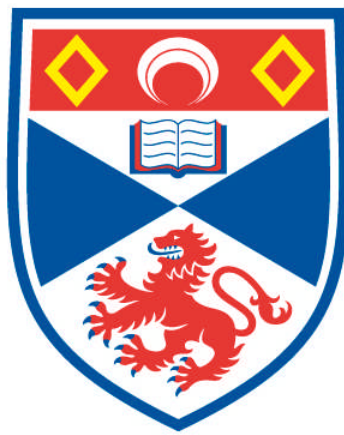


**THE VICTIMS OF A SORTED LIFE :
AGEING AND CAREGIVING IN AN AMERICAN
RETIREMENT COMMUNITY**

Philip Y. Kao

**A Thesis Submitted for the Degree of PhD
at the
University of St Andrews**



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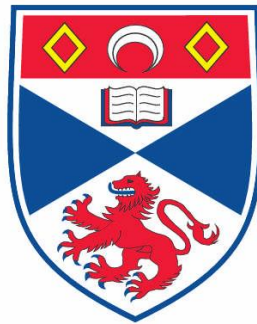
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The Victims of a Sorted Life: Ageing and Caregiving in an American Retirement Community

Philip Y. Kao



This thesis is submitted in partial fulfilment for the degree of PhD
at the
University of St Andrews

10 June 2013

University of St Andrews
Social Anthropology

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COMMUNITY**

Philip Y. Kao
PhD Thesis

For My Family

“In the animal kingdom, the rule is, eat or be eaten;
in the human kingdom, define or be defined.”

--- *THOMAS SZASZ*

ABSTRACT

This thesis is an ethnographic analysis of a Continuing Care Retirement Community (CCRC) in the American Midwest. I examine salient aspects of American culture, and how persons in the American Midwest understand relationships and themselves in the context of eldercare, and particularly, how issues of personhood and kinship are conceptualised in a long-term care facility. Rather than focusing exclusively on just the labour of caregivers, or how the residents in the CCRC receive care, my study is grounded in the interaction and relations that obtain during specific regimes of caregiving. Because the exigencies of ageing are met with certain exigencies of care, this study touches upon three dominant themes that make sense of the tensions that emerge when principles and practices do not square up. The first theme deals with how ageing and care are constituted, and made relational to one other. Secondly, I demonstrate that in the CCRC where I conducted fieldwork, ageing is constructed as a process and institutionalised, resulting in a distinctive way in which space and time are dealt with and unravelled from their inextricability. The resulting consequences affect not just the older residents and the CCRC staff, but also impacts how caregiving takes on specific forms and meanings. Thirdly, I investigate how formal (professional) caregivers and care receivers produce a type of social relation, which cannot be understood alone by conventional studies of kinship and economic relations. Ultimately, this thesis sets the frame for future debate on the ontological commitments involved in eldercare, and how the segregation of care and of the elderly in society relate to wider social norms regarding ageing and marginality.

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ACRONYMS

Activities of Daily Living (ADLs)

Bowel Movement (BM)

Centre for Health and Rehabilitation (CHR).

Certified Nursing Assistant (CNA)

Certified Therapeutic Recreation Specialist (CTRS)

Civil Rights of Institutionalized Persons Act (CRIPA)

Clostridium Difficile (C.Diff)

Continuing Care Retirement Community (CCRC)

General Practitioner (GP)

Health Insurance Portability and Accountability Act (HIPPA)

Mini-Mental State Examination (MMSE)

LPN (licensed practical nurse)

Long-term Care Facilities (LTCs)

Medical Technician (med tech)

National Public Radio (NPR)

Nursing Home Reform Act (NHRA)

Obsessive-Compulsive Disorder (OCD)

Position Description (PD)

Skilled Nursing Facility (SNF)

United States of America (US)

US Department of Housing and Urban Development (HUD)

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Introduction

i) Ageing and an Anthropology of What

The physical marks of ageing are undeniable, and they are familiar to everyone. Even Siddhartha, who was once kept from seeing senescence at an early age, eventually cast his eyes on disease, poverty and old age frailty. Despite one's recognition of mortality, ageing can never be disassociated from the looming prospect of death. One can ask of course, what agency does a very old person have besides simply just waiting for time? And so the teleological story goes, as one grows older, death creeps closer. Contemporary western society wages war on ageing; the issue is not just about longevity and the desire to continue experiencing, and consuming, but also about capturing and sustaining youth in perpetuity. Therefore, what is or can be eked out of our final hours?

For the residents in a nursing home, death is not a constant bogeyman, keeping people up at night. Death is a common occurrence in the nursing home, but it is assigned moral valences and significations according to differing personalities, contexts and the way specific acts of dying are seen to give meaning to one's life course, much like the final chapter of a novel. Therefore, and apart from any clinical bouts of psychosis, death does not provoke constant anxiety in the nursing home. Rather, death is like the sun, something you can look at but not for too long.

The topics of age and ageing are not new to anthropology. Age groups, sacred elders, rites of passage, age and gender, and age as a social organising principle have taken up centre stage for many in the discipline (Fortes 1984 , Glascock 1990, Goody 1958, Kertzer and Keith 1984, Maybury -Lewis 1984, Rubinstein 1990). It was not until shortly after WWII, that cultural anthropology in America decided to gaze upon the treatment of the elderly in light of its own society's 'culture and personality' (Clark 1967).

The nursing home has been somewhat of a fascination for social scientists (and some anthropologists) who sought its social world and 'institution' as a new ethnographic possibility (Gubrium 2009, Keith 1977, Henderson and Vesperi 1995). Many ethnographies and research projects detail the daily lives of nursing homes, providing a descriptive and emic account of its contested cultural domain through residents, and from the perspectives of front line caregivers and nurses (Carder 2003, Diamond 1986, Gass 2004, Gubrium 1993, Ice 2002, Johnson 1987, Kayser-Jones 2002, Laird 1982, Savishinsky 1991).

There have been plenty of nursing home ethnographies, some of which foreground the helplessness and frozen liminality older people face in institutional prison-like settings. We have for example, the work of Renee Rose Shield, which details the passivity and loneliness of nursing home residents (Shield 1988). Shield argues that residents are trapped in a liminal space between a lifetime of meaningful ritual passages, and death as the unwanted final rite of passage. She describes the lack of ritual and *communitas* among nursing home residents, resulting in an uneasy ending for her informants (Shield 1988). Judith Okely, prompted by the personal experience of her mother's ageing and dying, has also written about the subject of love, care and diagnosis, including a very sombre article (Okely 2001). Meanwhile, Barbara Myerhoff's classic account of storytelling and ritual among a Jewish community of elders shines on as an optimistic gem. Her works stress the importance of ritual and storytelling for the elderly as part of their psychosocial health (Myerhoff 1978, 1979). Early US-based nursing home ethnographies have also documented how persons come to be passive recipients of care. Jules Henry's account in *Culture Against Man* (1963) of the devaluation of older persons in American nursing homes continues to conjure up the failures and the impersonal nature of nursing homes. These studies have paved the way for showing us how mortification of the self (Goffman 1961) is linked to various institutional practices and ideological constructions. In the UK, current ethnographic studies of care have taken on a slightly different approach. For example, Jenny Hockey argues for incorporating non-Western ideas of personhood into palliative care situations (Hockey 2008). Rather than treating the 'self' as a 'container of identity', examining how the boundaries of bodies can be challenged and fluid is key for her to reversing institutional stigma and social death. The focus on the body leads out into the nexus of contexts. On

the one hand we have the shifting political economy. Peace, Kellaheer and Willcocks argue that the ethos of residential care is changing; the care industry as a profit business affects the way policy-makers and anthropologists will have to reconsider the analytical divisions between nursing home (medical) and residential care (social) models (Peace, et al. 1997). Meanwhile, there has been a focus on new social environments and ageing. Several anthropologists have been keen to study for example how new residential projects are reconceptualising the tensions between the public and private, domestic and institutional living arrangements, and the interactions between persons and their environments (McCourt 2000, Peace and Holland 2001).

In a collected edition of essays entitled, *Gray Areas: Ethnographic Encounters with Nursing Home Culture*, the various authors comment on the 'state of being in limbo' by exploring the idea of home versus hospital, and the relationships and situations that manifest in the nursing home (Stafford 2003). Residents also struggle to obtain timely information and understand the decisions that are often made on their behalf (Kayser-Jones 2003). Despite this, and the fact that most residents rarely engage in any meaningful social activity with their fellow residents as friends, and in a system that separates medical care from life and social relations, they do find ways to re-establish themselves. Sometimes residents resist certain foods, while drinking and smoking against their care plans and family's wishes. In other instances, where caregivers and nurses are negligent and absent, residents rely on one another, forming new interdependencies (Ryvicker 2009).

A relatively new discourse is also emerging which is focused on a nursing home culture-change movement in an effort to empower (and reverse the de-skilling of) caregivers so that they can deliver resident-directed care (Rahman 2008). It is this kind of resident or rather person-centred care that is at the heart of this emerging discourse, focused on the promotion of: 'autonomy, and self-determination, and emotional and social wellbeing' (Brownie 2011, 64). Medical anthropology has contributed to the study of ageing, especially when ageing is coupled with diseases such as Alzheimer's and dementia (Cohen 1998, Henderson 2003, Leibling 2006). Anthropological investigations into dementia-related conditions draw from phenomenological approaches to understand how memory, time and personhood interrelate. Kontos describes how people with severe dementia are able to express themselves through non-verbal

communication, employing a practice of embodied selfhood in the face of cognitive impairment (Kontos 2006). These studies also remind us that old age is not synonymous with disease, and furthermore that ageing in the absence of dementia still requires a lot of work and self-care when others are not around, or when caregivers are negligent.

What we have today is an even more complicated and less clear idea of what ageing and old age mean, entail, and say about the temporal, physiological and senescent aspects of human experience. Moreover, nursing homes have been changing; there are now a number of new long-term care facility models and communities that have grown in reaction to the overly medicalised and institutional feel of the traditional nursing home. It is also becoming more apparent that there has never really been a venerable golden age or society that has treated its elderly better, or that the west is somehow wicked and horrible toward its elders.

In American society, old age is still perceived with much ambivalence and fear. American society's concepts of age are stubbornly tied to cultural and ideological constructions of time, life stages, and proper codes and behaviours for 'normal ageing' (Clark 1967, Jung 1994, Oster 1984, Rubinstein 1990). Instead of treating age as a reified object that explains human behaviour, I take age and the process of ageing to be a place-marker in a debate, which is really about issues of social structure, relations, and agency. In other words, age is a social problem not because it exists in society, but rather ageing causes Americans to face up to the questions: Who will care for us? Who do I have to care for? What constitutes meaningful care? All of this is tied directly to a value system that favours independence, and self-reliance (Johnson 1987, Kaufman 1994). Because of this, coming to grips with a loss of independence and learning to depend on others is hard (Ward 2008). Ageing, or rather our conventional understanding of old age as a biological outcome and a social category (e.g. the status of tribal elders, grandparents, or even the plight of retirees) says little about the experiences of people in the later life course, and especially of those living in long-term care facilities.

I aim to go beyond simply a description of daily social life in an 'institutional' setting. By looking at how issues and expressions of independence and dependence play out in the

social relations among residents, staff, and their families, I will be addressing salient aspects of American culture, and how persons in American society understand relationships and themselves. These negotiations between understandings and instantiations of autonomy, independence and dependence constitute human development regardless of age or life stage. Toren's phenomenological approach to the "mind as a function of the whole person constituted over time in intersubjective relations with other in the environing world" is a good way to understand how people construe themselves as socially meaningful persons in relation to one another (Toren 2002, 193). I take the American idiomatic expressions and tensions surrounding independence and dependence as a dialectic in this intersubjective approach to personhood and sociality. Myerhoff and Simic state that ageing is work; in fact a life's career (Myerhoff and Simic 1978). Self-care is part of it, but also what occurs is the way we engage ourselves in relations based on our perceptions of independence and dependence. If the way we engage others is part of our own becoming, then issues of independence and dependence, as culturally inflected, play a role in structuring who we are (becoming). Ultimately the concern here is with persons and relations in and through time, and how issues of independence and dependence play out and influence the nature of social relations and the experience of life and ageing.

What is also interesting is a consideration of the caregiving relationship between particular people, and the relationship as a structural feature developing out of a wider social, economic, and historical context. My interest in ageing has to do partly with the industry and practice of caregiving and what this says about our social and emotional linkages to one another. This is not to say that I am interested in how people are (or are not) culturally obligated to take care of the sick or elderly. Rather, it is the intimate and corporeal relationship that unfolds between a caregiver and a care-receiver that illuminates what it means to be independent/dependent, whole/broken, and social in specific contexts. Caregiving then is never neutral; i.e. it can sometimes stand in as a metaphor for an assertion of (bio)power. I once heard a female caregiver in a nursing home confront a nurse about a particular resident. The certified nursing assistant (CNA) was trying to convince the nurse that 'her' resident was acting up and needed some medical attention. After the nurse neglected to pursue any follow up, the CNA walked away noting sarcastically, "Well what do I know? After all I am *just* the caregiver! I am

with her Monday through Friday” In other contexts, caregiving can be operationalized to assert a type of labour identification and experience. Caregivers often say to themselves that, “Not everyone can be a caregiver. It takes passion; you have to like taking care of people. Not everyone is cut out that way.” In that same conversation, another caregiver said, “It is an impossible job. Doing everything is still not enough!” In caregiving, the emotional dimension is far more complex than the sheer physical task of transferring someone out of bed, brushing their teeth, and getting them to various appointments while making sure that they are ‘toileted’ every two hours. In fact, caregivers themselves have developed a form of dependency as well. I overheard several times that, “If it wasn’t for my residents, I would have quit a long time ago.” There is a creeping suspicion (on my part) that caregivers need their residents just as much as the residents need them.

The caregiving industry can be analysed as a set of structural relationships, developing out of a wider social, economic, and historical context. Traditional nursing homes are being replaced by the sprawl of assisted living communities, Continuing Care Retirement Communities and other long-term care facilities. Carder and McLean have turned their attention to new spaces such as the world of assisted living facilities and the Green House Project—which is a spatial concept spawned from the Eden Alternative for designing more personal and homier nursing homes (Carder 2003, McLean 2006). For one thing, Continuing Care Retirement Communities incorporate many services and long-term care facilities and services in one location. The resident who transitions from an independent condominium to a unit which has more surveillance and nursing staff provides an interesting segue to explore how spatial organizations reinforce and reproduce practices, perceptions and relations of independence and dependence. The sterile nursing homes of the past will have nothing to do with the changing attitudes of the baby-boomers. They have witnessed the institutionalisation of their parents, and they will no doubt advocate for spaces of dignified living, new criteria for care, and new incarnations of home and kinship. For the formal caregivers, who comprise of a diverse work force, including pre-med and nursing students, and recent immigrants, the burdens on and expectations of them are immense. One of the underlying challenges remains: how much can we know about ageing, dementia and impairment if we do not actually experience these life transformations ourselves? It is this epistemological

abyss that caregivers are confronted with emotionally and empathetically daily. Therefore, attention must be paid to how caregivers make sense of their world and the life-course, because it is through their practices, both normatively and institutionally, that caregivers and their actions structure and shape the discourse of ageing. Caregivers do not just interface with the elderly by bringing them the outside world; they stand in for the world.

The relationship that obtains between caregiver and care-receiver is not fixed; nor is it a simple relation of static dependency or attachment. Rather it is on-going symbolic interaction or, more subtly, an historically constituted intersubjective relationship which generates analytically interesting transformations of existing relationships and people's sense of themselves vis-à-vis others and their feelings about ageing and death. Even though caregiving appears to be just manual labour, the relationships that are forged and the nature of the intimacy involved in caregiving rub off on workers in interesting ways. I witnessed how caregivers try to maintain empathic distance at times with their residents.

An anthropology of caregivers can seek to address what actually constitutes care in various cultural settings and societies. Is 'care' a set of (performative, monetary, et al.) functions which simply arises out of reciprocity and/or a moral ethic that forces us to look after the elderly, and in the ways that we do? In the future, will every ageing person be assigned a caregiver; what will happen to caregivers as they become older? What will be their expectations for the care and experiences they will have in old age? These are just a few of the questions regarding caregiving and caregivers that I seek to frame and advance for future debate.

ii) What is a Continuing Care Retirement Community (CCRC)?

CCRCs are often marketed as an alternative to the nursing home. For CCRC supporters and sponsors, they are positioned in contradistinction to the 'total institutions' of the traditional skilled nursing facility (SNF). SNFs provide residential care for people who require constant nursing services including significant assistance with the activities of daily living. In addition to helping people to get out of bed, go to the toilet, shower and dress, nursing aids and their assistants also monitor and administer medication. There

are formal staffing requirements for an establishment to be certified as a SNF. For example, qualified nurses must be on hand twenty-four hours a day. Therapists also helped residents in the SNF with strategies dealing with how to cope with vision impairment, fall prevention, and customised speech therapy development programmes. This is not the place to delve into the history of nursing homes, but it is important to contextualize when the rise of CCRCs took hold over the landscape of American ageing and retirement.¹

In 1980, the Civil Rights of Institutionalized Persons Act (CRIPA) was passed in order to establish standards regarding the quality of life, health and safety of persons living in state institutions. This federal law sought to protect the civil rights of people in places such as juvenile facilities, prisons, psychiatric hospitals, and nursing homes. The federal Nursing Home Reform Act (NHRA), known today as Title 42 Part 483 of the Code of Federal Regulations, was passed in 1987. According to NHRA, nursing homes must ensure that their residents are protected against physical and mental abuse, corporal punishment, involuntary seclusion, and the use of physical and/or chemical restraints that are not part of prescribed medical treatment. The NHRA sought to set minimal standards so that nursing homes, and particularly SNFs, had adequate staff and that they were providing appropriate skilled and non-skilled services. These laws ensure that nursing homes residents have privacy, and are not abused or neglected in any way. Moreover, the NHRA also requires nursing homes to communicate honestly and upfront with their residents about fees and treatment plans, and to allow residents to participate (somehow) in the administration of the nursing home.

The CCRC model emerges from a history of traditional religious and community-based models of senior living. One can see historical analogies in the case of the Indian ashram, early Christian almshouses, or even the poorhouses dedicated to some of the elderly immediately after the American Civil War. The modern-day CCRC really flourished and began developing across the United States in the late 1970s. According to a 2009 report put out by the Ziegler National CCRC Listing and Profile, there are about nineteen hundred CCRCs in the United States. The majority of which were purpose-built CCRCs. The report also states that about half of the CCRCs in operation today are faith-

¹ See Carole Haber and Brian Gratton's *Old Age and the Search for Security: An American Social History* for a good discussion of the history of nursing homes in the U.S.

based; other sponsors such as universities and fraternal organisations are also involved in backing CCRCs. Moreover, 82% of the CCRCs are run as not-for-profits while just 18% have for-profit ownership. CCRCs are not federally regulated; regulatory oversight is provided via state legislation, and as such, varies from state to state.

CCRCs allow customers to alleviate the stress of moving right into a SNF by allowing them to buy into a lifelong contract, usually financed via the conversion of home equity into CCRC housing. By doing so, the person can 'age in place', allowing them to move within a community and institution they are already accustomed to. Those who are drawn to the CCRC option often say that making a decision for their long-term care future before it is too late is not only responsible, but gives them a sense of empowerment. Additionally, people say that the decision has not only alleviated stress for their families and loved ones, but has also given them peace of mind. For Netting and Wilson, "[...] persons who want to travel, know that their home is taken care of, reduce their responsibilities in terms of maintenance and oversight, and perhaps feel that they have gained a little control over life's uncertainty, the CCRC is likely to remain a viable option" (Netting and Wilson 2006, 674). The CCRC also offers a variety of housing options, and a variety of services and amenities such as a beauty salon, dining facilities, fitness centres, golf putting greens, convenience stores, and fieldtrip excursions. Because there are different floors and sections of the CCRC assigned to people's various needs and conditions, residents do not have to move to another external place no matter how they age. The CCRC model prides itself on this system of care delivery known as the 'continuum of care', which keeps residents in the same place, at least under one roof, so that they can continue their existing relationships with their neighbours and staff members.² Unlike the traditional nursing home, CCRCs allow residents to remain in one institution or rather campus, enabling them to move in accordance with their (so-called) needs and levels of care.³ In other words, CCRCs are designed to allow people to age in place. The rationale behind the CCRC is that internal moves within an institution are less stressful than external moves, and that transitions

² Netting and Wilson also note interestingly that: "In trying to put together a continuum of care in one campus-like location, CCRCs essentially spawned the concept of assisted living as an option between independent living and nursing home care" (Netting Wilson 2006, 674).

³ For a history of the CCRC, see (Conover and Sloan 1995) and (Humble and Ryan 1998).

can be better monitored and controlled. Borrowing from the work of G.J. Andrews, health care places such as CCRCs can be seen as ‘therapeutic landscapes’ or rather contextual settings that are complex and full of symbolic constructions (Andrews 2004, Pranikoff and Low 2007). For some, CCRCs are therapeutic because they allow caregivers and care receivers to “[...] understand more about how transitions in activities are related to the various dimensions of well-being in older adults” (Cutchin , Marshall and Aldrich 2010). CCRCs attempt to provide a sense of security by guaranteeing that someone will look after you no matter how you age. The CCRC trades not just on cultural ideas of fear, doubt and uncertainty when marketing to senior citizens and their adult children, but also on safeguarding the importance of independence. CCRC brochures and marketing pamphlets state that they are committed to assisting residents achieve their highest level of independence and that with their services, residents can get on living their lives.

Therefore, CCRCs are different in design from the nursing or ‘old folks’ home one usually imagines. They are part home, and part activity and healthcare centre. They represent an attempt to institutionalise the ageing process, by matching up a gradient system of care with a conception of ‘phased living.’ The fee structures of CCRCs can also be hard to navigate. In today’s CCRC marketplace, there are three types of arrangements, and each CCRC may offer a different type of contract. Type A contracts are known as ‘extensive contracts’, whereby residents pay an upfront fee and continuing monthly fees in exchange for lifetime care and a guaranteed place of accommodation, without an increase in monthly fees as they move to different levels of care. Type B contracts are modified contracts wherein residents have lower initial fees, but if they later require more nursing services an increase in monthly fees will follow. Type C contracts are also known in the industry as fee-for-service contracts. Residents usually pay a lower entrance fee, but they are not given any discount in health care services. Residents under contract C, pay market price for any change in their long-term care, thereby shifting a major part of the risk associated with ageing and decline away from the CCRC. Because the fee structure can be complex and is a major investment, the United States Senate Special Committee on Aging released a report entitled *Continuing Care Retirement Communities: Risk to Seniors* on July 21, 2010 in order to publicise some of the consumer investment risks associated with the CCRC business model (and

especially in light of the period's economic downturn and stagnant housing market). In a piece entitled *CCRC Fees: Prepare to Be Bewildered*, Paula Span writes in a New York Times blog⁴ that, "[CCRC] Price tags vary enormously, reflecting not only regional costs of living and amenity levels, but also contract types" (Span 2009). One of the comments posted immediately following Span's blog entry reads, "True that CCRCs are expensive. But after 8 years of aging in one of them, my wife and I can testify that they are the best solution to winding up lives. The burden of needed care is off the backs of spouses and children, many details of normal living (house cleaning, driving to shop, etc.) are eliminated. Aging bodies and minds are eased [...] CCRCs are a great development for a civilized society." Another contributor hours later posted the following: "Besides, if you think CCRCs are complicated, have you looked at our cell phone bill lately?"

The CCRC is not a village where all of its inhabitants are older than 65. Nor is it a microcosm of society, where everything is conveniently located under one roof. They were designed as a way to circumvent the stressful move from home to a hospital-like setting by staggering the moves under a phased kind of living arrangement. The people who championed the CCRC had in mind that ageing inevitably involves decline. By pooling people's resources and adopting a co-op like principle, they thought that ageing in place and collectively would offer some kind of assurance and security. What has been said of retirement communities in Florida for the active old, especially as their residents start to reach past 80 years old, can be just as valid in the context of some CCRCs: These senior living models are still at the end of the day an architecture of endemic loneliness. The tragic irony, which has not been lost on anyone, is that no one wants to be reminded of getting old. Ageing with others is a lonely endeavour. Being with only your age cohort produces the same kind of loneliness that Citizen Kane must have felt eating in his Xanadu. Phased living in a CCRC is modelled after a series of declining steps, an everyday tug of war against further slippage and the moves that will undoubtedly take hold.

The CCRC is a place oriented towards the view that ageing in late life brings about decline and regression. The CCRC is not only a long-term care facility about meeting people's current needs, but also a place that people's future selves will inhabit. An

⁴ The New Old Age: Caring and Coping blog can be accessed through:
<http://newoldage.blogs.nytimes.com/>

analogy might help here: it is like giving someone young a pair of shoes slightly too big, with the expectation that they will grow into them as they age. If the future is bleak and characterized as one of loss, then the CCRC strives to function as an insurance policy to cushion the fall, so to speak. This causes, however, a nervous anxiety and an even more paranoid stance towards the life course and ageing. The ultimate fear is not death but rather the consequences of impending disability. Independence is being able to take care of oneself. Meanwhile, the social clock of work, retirement and leisure lose their foothold in the CCRC. Thus, one can view the CCRC as a kind of cultural design. In an edited book on ageing, entitled *Anthropology and the Riddle of the Sphinx: Paradoxes of Change in the life Course*, Ladislav Holy reveals how the Berti of Sudan seek out various strategies to secure support in old age. The Berti influence marriage strategies, and allocate property to children upon their marriage. By doing so, not only do they aim to secure the labour of their grandchildren but they are also securing a place for themselves to age. Holy states, "It is [the Berti's] perception of their own position in the future rather than their contemporary interest that motivates the cultural engineering in which they are involved. It thus need not necessarily be old age as such but the vision of old age that can be usefully seen as enforcing specific cultural practices" (Holy 1990 , 180). In this light, the CCRC is just that, a systemised delivery of care as a way of negotiating an uncertain and oftentimes unpleasant future. Care is not only palliative, but also in its most ideal form preventive. Holy goes on to state, "People do not simply behave in a certain way because they have reached a certain stage their life course. They envisage the future stages in their life course on the basis of the experience of those preceding them and plan for their own future on the basis of this experience when they are in the position to do so" (Holy 1990, 181).

What the CCRC puts into relief beyond its own temporal structuring is just how life is experienced by those who are its residents. Haim Hazan points to the near impossibility of ascertaining the "existential nature of [ageing's] experienced meaning" (Hazan 1990, 190). He states eloquently that, "Unlike other liminal phases where social marginality is furnished and reconstructed by the surrounding society, the ambiguities of ageing constitute a normative vacuum which acquires meaning only through the behavior adopted by its incumbents—the aged" (Hazan 1990, 183). The elderly, for Hazan as for many anthropologists who study ageing in the context of nursing homes, are trapped in

a frozen liminality, “a sphere of existence where past relevances and future prospects no longer inform the present” (Hazan 1990, 190). It my intention that by focusing on care as a set of practices, and a vehicle of transactions and socially emergent relationships, the gulf between the social organization of ageing and its meaning(s) can be bridged analytically and interpretatively.

iii) Methodology

I conducted fieldwork from November 2009 – July 2011. During this period I immersed myself in the life-world of Tacoma Pastures, a Continuing Care Retirement Community (CCRC) located on the outskirts of a university town in the American Midwest. I did not enter the field site with any rigid analytic perspective or a set of survey questions. Rather, like Jaber F. Gubrium’s groundbreaking book-length ethnography of an American nursing home, *Living and Dying at Murray Manor* (1975), my ‘Murray Manor’ took some time in opening up itself to me before it became a proper field site. Initially, I was drawn to many overlapping interests. I recalled visiting nursing homes as a young student, and mainly during holidays to chat with elderly residents. On some of these occasions, I even performed the violin in small chamber group ensembles. My memories of these nursing home visits, images of the older residents, their gestures, and what I felt at the time as my alienation from them as ‘authentic’ human beings stayed with me. Years later, I began to notice that long-term care facilities in the form of apartment complexes, senior living communities, and assisted living ‘villages’ were pockmarked along highways and becoming just as ubiquitous as shopping malls in the Midwestern suburban landscape. My image of the traditional nursing home as a red-bricked edifice confined to the rolling hills of an estate on the outskirts of town was being obliterated.

I was interested in ageing and the plight of the elderly in society even before I started thinking about conducting ethnography. I recalled a particular conversation I heard several years ago while sitting in the DC Metrorail between two older women, who were bemoaning the fact that they were invisible in society. One of the women said to the other, “It’s just like New York, but worse. People see right through you. It’s like old people don’t even exist.” I wanted to embark on an ethnographic project that dealt with ageing from a social perspective. Certain conventions in social anthropology suggested

that I should study people who are significantly different from me. Even though I grew up in the American Midwest and shared many of the same cultural references and social institutions as my informants, the residents in the CCRC were significantly different. The majority of the residents could claim European heritage of some sort; many of them were second-generation immigrants. Additionally, most of the Tacoma Pastures residents were at least two generations older than me. Therefore, my research was an 'anthropology of home' in two senses of the word. I was familiar with and a product of the society I was investigating, but more than that, I was conducting fieldwork in a 'home'.

My fieldwork centred on a specific CCRC, but I never committed myself to a study of just its workers, or its residents exclusively. More generally, I wanted to know how people lived out their lives in these places, and whether or not residents were simply dropped off and abandoned by their family members. Additionally, I also recognised that depending on one's enframing, the ethnographer would have to juggle between different analytical perspectives and registers. There is first and foremost the institutional context, which would inevitably bring in the usual Goffman-esque and Foucauldian style line of argumentative constructions. Secondly, the organisational perspective of how nurses and workers manage 'patients' and 'care' presents the researcher with yet another 'side of the story', one directly in dialogue with an anthropology of labour. Thirdly, an account of the resident as an ageing person struggling somewhere between institutions and practices suggests a particular narrative about personhood and western autonomy and dignity.

These levels are 'real' and no doubt play into the dynamics and cultural obviation of the ethnographic method and its subsequent interpretation. With all these issues in my back pocket, I still ventured into the field with a fairly open-ended and even naïve set of questions, which took inspiration from my outlook that studying how old people are taken care of and treated in a long-term care facility would offer some insight into American contemporary middle-class white society. Conceptually and gradually, I became interested in exploring how culturally-inflected ideas of independence and dependence might come into being, and shape the social experience of ageing. I wanted to see whether or not ageing in a Midwestern long-term care facility in America was less about life stages, or even medical problems, but more about the unfolding and changing

nature of social relations. I was convinced that treating ageing simply as a biological fact or a cultural construction said very little about the experiences of people living in long-term care facilities. Focusing on these residents, I reminded myself during the early period of my fieldwork that how these people made sense of and managed the interchange between actual and perceived losses of independence (e.g. physical, financial, self-care, etc.) and the relationships that emerged from these evolving dependencies would be something to take note of.

Some other heuristic questions began to arise during my familiarisation with Tacoma Pastures as a field site: Why was care so ineffective and made to seem complicated? How did long-term care facilities become so accepted in the West in such a short period of time? Furthermore, why was it that despite the majority of people's fears and apprehensions regarding long-term care facilities, why did people still constantly move into them? This tension and anxiety commanded my initial research attention. Unlike Gubrium, who fell into his ethnographic method unknowingly after familiarising himself with Murray Manor and its residents over a brief period of time, I knew that I was going to engage in a kind of ethnographic enterprise rooted in participant observation. But even with this in mind, Tacoma Pastures had not yet become my field site. In order for me to make sense of how Tacoma Pastures stood in relation to the rest of the community, I knew I had to widen my field site in order to incorporate other social groups, events and persons who were part of the larger context of ageing and caregiving in society. This was not going to be a strict institutional ethnography.

Over the course of twenty-one months, I engaged in systematic participant observation. For the first nine months, I conducted research and volunteered at Tacoma Pastures. For the remaining twelve months of fieldwork, I continued my role as a social anthropologist researcher, but now I was working simultaneously in Tacoma Pastures as an official part-time caregiver. Over the course of my fieldwork, I conducted semi-structured interviews with Tacoma Pastures workers, residents and their family members. Additionally, I ventured out of Tacoma Pastures and conducted research in community senior recreation centres, sitting in on various caregiving support group meetings—mostly geared towards persons with family members suffering from dementia. I visited other long-term care facilities in the area, as well as attended community presentations on elder law (e.g. touching on such topics as power of

attorney, and wills/trusts), and caregiver retreats. Fieldwork also took me to hospitals, local hospices, memorial services, churches, caregiving training sessions, and funeral homes. I also conducted interviews with local general practitioners (GP) (geriatricians, and internal medicine doctors), elder law attorneys, and funeral directors.

My initial research design loosely followed Keith's three-phase approach to participant observation in ageing communities (Keith 1986), but rather than adhere to Keith's particular sequencing, I was simultaneously collecting data across a range of contexts. I mapped the social space of residents and staff throughout the entire CCRC, and ascertained where people lived and how they related to one another. I had access to resident-to-resident, resident-to-staff, and resident-to-family member interactions as they appeared and played out before me in the social life of the CCRC. Identifying who had moved from independent to more dependent living apartment units at Tacoma Pastures became something I had to take note of as well. Additionally, I familiarised myself with many of the residents through personal visits, and consultations with the staff regarding resident care plans. Attending various resident committee and staff member meetings gave me another set of data to contextualise and analyse. While all of this was happening, I was seeking out conversations with various members of staff including those working in the kitchen, recreation, and laundry departments.

Even before I set foot in Tacoma Pastures, I wrote a letter requesting permission to conduct fieldwork. I introduced myself as a doctoral student of social anthropology, and I informed the Director of Tacoma Pastures that I wanted to research ageing and long-term care issues at Tacoma Pastures. My letter was met with surprising enthusiasm. The Director of Tacoma Pastures suggested I meet with the Risk Manager, and we discussed what and how I was going to go about my research. Since Tacoma Pastures was situated on the edge of a fairly large university campus, they were accustomed to hosting various research projects. Nurses, occupational therapists, medical students and geneticists frequently conducted research with and on Tacoma Pastures residents. Given that the Risk Manager did not deem my research 'medical', I did not have to sign any waiver forms. It was only when I was hired as a part-time caregiver that I had to sign some official forms pledging my adherence to the governing rules of Tacoma Pastures and various state laws. I had to promise to uphold the confidentiality of my

residents, and to abide by the government Health Insurance Portability and Accountability Act (HIPPA) rules on privacy.

Throughout my research and writing, I employ the use of pseudonyms. Also, I obtained informed and signed consent for every interview I conducted with the residents. With that said, full disclosure, that is letting every resident and his/her family members, and every member of the CCRC know that I was conducting fieldwork would have been impossible. I was thus governed more by a simple and practical principle, suggested to me earlier on by Jaber F. Gubrium in a personal email: I would be “led by a simple principle of doing no harm than the current legalistic criteria, whatever they are, that are met in terms of the letter of the law, rather than the spirit. Poor subjects; pity society.” Part of the reason I was so welcomed in the beginning also had to do with the fact that my research interests were in line with some of the projects they were looking to get started on. Tacoma Pastures kept some records of its early years, including various archival materials detailing whom the residents were, along with some of their diaries and narrative accounts.

The Director was looking for someone to help compile an unofficial history of Tacoma Pastures in addition to interviewing residents who could remember some of its earlier years. I was more than happy to take this on, but more than anything else, the Risk Manager was also looking to put together a report for the Tacoma Pastures’s Board of Directors on whether or not residents were receiving ‘person-centred care’ and ‘quality customer service’. She felt that my outsider’s perspective would help her with the report. Even though nothing came to fruition with the latter, I did manage in the end to help Tacoma Pastures organize some of their historical records, and even found some materials to add to their archives. Because I was a researcher and a volunteer/caregiver at the same time, I had to remind myself of the dual nature, and ethics of what I was doing. For example, I always treated the resident and my job responsibility to him/her as my first priority. My research was going to always come secondary, which meant for instance that I had to rely on my short term memory, writing up my field notes at home at the end of my work day. I did not engage in any experimental research or ethnomethodology, which would have compromised the residents in any shape or form. Of course juggling multiple roles is problematic; many of the tensions born from being a researcher and a volunteer/caregiver simultaneously adds to this ethnography’s

particular shape and narrative form. Even though there is an autoethnographic component to how I became a caregiver in the first place, I had to analyse the changing social relations I found myself to be a part of. This was something I couldn't ignore. For one thing, as a caregiver I soon sensed that workers just as much as the residents were at times at the mercy of a business model which meant that there were just not enough caregivers and time to go around. It was not just the residents, but also the caregivers that felt the stress and consequences of a system that was underfunded and by nature alienating. A fuller treatment of my positionality and the changing social roles I had to negotiate will be addressed in the chapter to come. For the moment, however, it is appropriate to mention that being a 'male-caregiver' of Asian descent meant that the people at Tacoma Pastures reacted to me differently. It was assumed that I was some kind of a pre-med student, and that being Asian, somehow meant that I was more 'sensitive' and respectful of elders. Residents saw me initially as a bit of a curiosity, while others never let go of that image. For example, one woman resident on the fourth floor always addressed me as 'Chan.' Being non-white also helped me get along with the other caregivers and workers, especially the kitchen and dining room staff that were mostly born outside of the United States. Being a male-caregiver meant that some women residents were opposed to me helping them shower; they were okay with me helping them with other tasks though. Some women residents even preferred 'male-caregivers', as one resident told me. Janelle, a woman who was losing her hearing, told me that, "male-caregivers are stronger and can move me more securely [...] sons are raised to respect their elders more than these girls these days."

It is perhaps necessary to say that conducting research on the elderly entails critical listening. There are competing and overlapping narratives. Contrary to popular belief, 'old people' do not simply recount their entire life stories, just because they seek attention. There are narratives of pain, and narratives of silence, and narratives residents think you want to hear. For the staff at Tacoma Pastures and residents, 'ageing in place' is an institutional representational artifact just as much as it is an actual presence in the resident's daily lives. I agree with Gubrium when he says that, "People not only tell stories, but at different times and places [...] Stories untold in certain circumstances, for example, can serve to silently support a prevailing discourse of experience" (Gubrium and Holstein 1999, 570). Gubrium asserts that there is also a

border and tension that obtains between narrative forms of representational authority and ethnography, and that this border is necessary to keep problematised rather than trying to dissolve it. According to Gubrium, “We must learn to live and profit from the inherent tension found in the interplay between voice, social conditions, and our own authorial aspirations” (Gubrium and Holstein 1999, 571). If anything narratives are never foreclosed, even after writing them out. They belong to a specific moment in time between two people. The conversations I had with residents and staff workers were instances where we were trying to create some meaning, oftentimes in an intimate setting. Sometimes I was talking to a resident in his/her room with the door closed; other times, I was talking to staff workers in the stairwell, coming and going between our daily tasks and duties. In most of these cases, I do not take narratives as final data points in and of themselves, but moments where my informants and I focused our searchlights looking for a common ground. We were afforded plasticity, of opening up to others and to regimes of care and institutional routines that caused us to put our daily narratives forward constantly in a shared meaning system.

Even though Erving Goffman and Michel Foucault’s work on social institutions and the ways people interact with each other, and in reference to the regulating power of discourse are definitely relevant to my social analysis of the long-term care facility, I am not simply conducting a Goffman-esque or Foucauldian-style analysis. For one thing, ageing is a complicated process that is ever-changing. It is not just the case that people are living longer, but rather ageing is a social fact of life that exists beyond the confines and predicative power of any ‘totalising’ institution. No institution as such, and even as a set of power relations and concepts can contain or fully dictate the ageing process. Because almost everyone in my field site expects to grow old and age, and because each person’s experience of ageing is quite unique, the language and concepts of Goffman and Foucault only go so far to capture the phenomena of ageing and caregiving. Ideas of institutional selves and ‘embodied selves’ suggest that places like the nursing home function to try and normalise the experience and meaning of ageing. Places like Tacoma Pastures, with their levels and regimes of care, certainly categorize people according to their progress and debilities. They also attempt to stabilise a set of narratives regarding care, ageing and customer service. Yet to go so far as to say that the long-term care facilities are responsible for making people old and elderly is perhaps off the mark.

For Goffman, the 'self' is situated and presented dramaturgically in the everyday. In his classic book *The Presentation of Self in Everyday Life* (1969), Goffman offers up a social construction model of the 'self' that champions the performative aspects of construing and identifying 'selves'. But what about the preservation of the 'self'? What happens when there is no stage or audience? Such an insistence on the self as a performance leads us to focus only on words such as agency, and autonomy; as if the preservation of the self was a game theory of psychological one-upmanship, and a play of interactive rituals. In his text *Asylums* (1961), Goffman argues that the patients and the staff's behaviours were modified by their interactions with each other and their experience of the mental hospital. Learning the social rules and roles amounted to becoming institutionalised totally. In the case of Tacoma Pastures, the 'self' was not being constantly presented. The residents were often in pain and just physically tired. It is not always the case that the institution dictates everything. Sometimes the residents operationalise a new set of expectations, relations and understandings of care and best medical practice that the institution has to accommodate. For example, when one resident lost her spouse, she went through several months of depression. Rather than transferring her out into a geriatric psychiatric ward, Tacoma Pastures decided to keep her in her old large apartment. This meant, however, that the care plan and routines had to change completely for the whole floor, because she required a different set of eyes and surveillance. Even fear and time bodies forth from each person differently, and rather than stubbornly focus on concepts such as resistance and control, by opening up the analytic space beyond the gaze and ordering of the institution, we can live into the reality that there is an exhibition of various aging and caregiving interpretations.

Similarly, but in a different vein, Foucault's rhetoric of (bio)power and his treatment of the disciplining practices and technologies of the self, afford a kind of purchase on the ageing body. Even though Foucault would disagree with Goffman's separation of the total institution from the rest of the world 'out there', Foucault is still interested in how institutions and the relations of power come to shape and control the existence of accepted subjectivities. But no one in Tacoma Pastures, from the caregiver all the way up to the management is interested in controlling or even entertaining the idea of halting the ageing process. They are keen, however, to control a person who has become a 'behaviour', that is a person who is resistant to care and violent. Medical practices

offer palliation and there is a general desire for healthy longevity, but the unpredictable nature of ageing and the immanent reality of mortality at the end of the tunnel work to keep people at a scared and humble distance. What the staff at Tacoma Pastures does want to control is the way customer service is linked to certain definable expectations and risks that family members might have to use in order to make sense of how and why their ageing loved ones are living out their lives in a long-term care facility. Therefore, although Foucault does offer us a more nuanced and historical examination of the sources and forms of control, a long-term care facility is not entirely about control, whether in the form of controlling persons or in the case of controlling social and unwanted bodies.

In the long and short of it, no one is really in charge of the 'institution'. The persons who reside at Tacoma Pastures take their cues from others, and from the rules and legal and financial guidelines set in place. Likewise, Tacoma Pastures is constantly adapting and updating to reflect changes in social policy and medical practices. To rely too much on Goffman and Foucault would necessarily lead us astray from the exigencies of ageing and caregiving that cannot be structured or encased by the terminologies surrounding the more straight forward studies of institutional ethnographies. In this way, Tacoma Pastures is the field site and the problem, the medium and the message.

Part 1

Chapter 1: Tacoma Pastures: The Past and Present of a CCRC

The idea behind Tacoma Pastures originated in the fall of 1964, when a State Conference of the United Church of Christ established a local ministry (Joint Church Manors) to look into and proceed with plans for housing the university town's elderly. In 1966, board members of the Joint Church Manors, the ministry formed by the United Church of Christ and the eventual sponsor of Tacoma Pastures, purchased the Roosevelt Hotel with plans for renovating it into affordable retirement housing. A fire damaged the building, however, and plans had to be revised.⁵ The board wanted to accommodate its friends and various parish members with an affordable place to live, partly because their relatively high incomes prohibited them from qualifying for a place in federally financed low-income housing.

During this time, Rev. Charles Tate, a United Methodist minister appointed as parish minister of the university's interdenominational Protestant congregation said, "There has been a rapid increase in the number of nursing care beds in the area, but we have not been building adequate housing for active retirees."⁶ Even though there was already a three million dollar retirement centre being built in an adjacent city⁷, Rev. Tate had a vision. He wanted to see local Christian churches cooperate for the purpose of erecting a Christian retirement community, perched prominently on a small hill and nestled among the tall verdant forest of pine, spruce and ash trees. For Rev. Tate, Tacoma Pastures would be, "a modern expression of Christian concern for older people, offering a full, purposeful and rewarding way of life in a congenial environment and pleasant surrounding."⁸ Rev. Tate and several other people who were deeply involved in the Tacoma Pastures project soon started taking board members and potential

⁵ Another informal account has it that the board considered renovating the Hotel Roosevelt under a program funded by the US Department of Housing and Urban Development (HUD), but the idea was abandoned when they found that HUD funds were indeed not available.

⁶ Quote taken from a local newspaper article announcing the Tacoma Pastures initiative

⁷ A corporation composed of United Methodist ministers and laymen was sponsoring this adjacent community.

⁸ Quote taken from Tacoma Pastures's first newsletter dated Spring 1972, Vol.1 No. 1

residents for one-day plane trips to visit a retirement centre in a neighbouring State. The ministers and layman interested in the project were so impressed by their visit to this retirement centre that they decided to model Tacoma Pastures after it.

Before construction could get underway, Joint Church Manors needed to raise \$15,000 in order to pay the developer for a feasibility study. A few people were able to donate a couple thousand dollars collectively, but when they still fell short, Rev. Tate mortgaged his home for the remaining \$9,000. The entire project was going to cost \$8,500,000, and this was financed in various ways. First of all, an initial mortgage was obtained from a local bank in 1972, covering a large part of the land, building, and furnishing costs. Additionally, Joint Church Manors offered a series of debentures denominated in \$1,000 units, and with various interest payments. Life leases contributed to much of the funding even before residents were able to move in. In an effort to boost resident numbers, discounts were offered to early applicants. Early applicants could save 5% on their life lease fees, and could lock in a rate of \$5.50 per day for 'skilled nursing care' and \$4.50 per day for 'basic nursing care' for their first year.⁹ Tacoma Pastures held many dinners and informational sessions. Joint Church Manors sponsored roast beef dinners in local churches, Christmas parties, and brunches at the Howard Johnson Hotel in order to get the word out. Tacoma Pastures was billed as an attractive and inspiring plan of Christian service dedicated to providing a solution to adequate housing for retirement living.

Actual construction began in February 1972. In its initial form, Tacoma Pastures was a five-story Y-shaped building located on a wooded and rolling 58-acre site. The entire complex included two hundred and forty-two individual apartments. Five apartments were used as early models for the marketing team, though there were sixteen different apartment sizes to choose from. A two-story solarium connected a three-story/seventy-bed health and therapy centre (also referred to as the complete nursing care facility) to the main residence building. With Tacoma Pastures's main entrance on the second floor, the attractive dining room overlooked a lovely wooded area and served as a hub of

⁹ Life lease fees generally amounted to a payment of roughly \$24,000 or the 1972 median price of a house in the Tacoma Pastures's area. A resident could choose to pay everything up front, or s/he could pay a fourth of the life lease fee as an entrance fee, followed by the rest of the life lease fee after moving in.

activity in the centre of the three wings. When the first ninety-eight residents moved in at the beginning of April 1974, they found themselves walking past a tastefully furnished lobby. Their apartments were clean, and colour-coordinated carpet, wall and tile selections were proudly on display; options available included beige, gold, green and blue. Each apartment had its own heating and air conditioning equipment, nameplates, refrigerator, bathrooms with tubs and showers, ample closet space, call system buttons (in case of emergencies), dual bedside stations with television, radio, AC power, telephone and lighting controls, and a communication system to reach the nurses' station. The large Alzada Penderson room located on the first floor provided residents with a space for various entertainment functions and meetings. The third, fourth and fifth floors were entirely taken up by residence apartments.

Resident applications were sent in and processed as early as July 1971. Letters were issued on behalf of the board informing applicants that their down payments were received. Enclosed in these letters were also examination forms to be completed by one's physician. Upon acceptance, the board issued another letter officially welcoming the future resident. In one of these letters, the board expressed the following: "You are to be complimented on selecting Tacoma Pastures as your future residence. The dignified and independent life style which you sought for your mature years will be yours as a resident of the Center."¹⁰ Tacoma Pastures marketed to a specific type of resident. According to an informational leaflet produced by the board members of Joint Church Manors: "Persons desiring residence at Tacoma Pastures must (1) be 65 years of age or more, (2) be ambulatory, that is, not confined to bed, and (3) be in reasonable good health for their age. In addition, residents must have financial responsibility and good ethical character." A roll call of early residents included the following professions: Teacher, secretary, homemaker, home economist, surgeon, professor, restaurant owner, serologist, and librarian. 'Security', well-balanced meals and the idea of having an extended care facility were reasons many people gave for choosing Tacoma Pastures. According to Mrs. Benrich, a person who "enjoys her retirement years—even to the point of laughing at her own foibles, the whole plan of residence and convalescent care if needed, makes good sense. The total security is something anyone my age ought to

¹⁰ From a letter on behalf of the Board of Directors of the Joint Church Manors to a newly accepted resident, following her application. The letter was dated: July 1, 1971.

seriously think about.”¹¹ Early marketing materials reiterated similar ideas: “A major benefit of retirement living at Tacoma Pastures is that residents will be relieved of the physical and emotional stress of maintaining a home and from the anxieties and worries concerning competent health and convalescent care should they become ill.” For some, moving to Tacoma Pastures was certainly stressful, and far more nerve-racking than the adventure many of them paid lip service to. For the board members, Tacoma Pastures was not just a real estate project, but also a spiritual endeavour. One board member emphasized to future residents in a newsletter column that: “Tacoma Pastures represents an innovative approach to solving some of the problems of older Americans. You will be able to give leadership from within.”¹²

Early residents formed an executive committee to act as a liaison between the residents and the administration. There was a president, vice-president, treasurer and secretary. Also, standing committee officers were assigned to look after such areas as food service, recreational activities, health and safety, religious services (e.g. vespers), the history of Tacoma Pastures, and even the centre library. Tacoma Pastures inaugurated its first few years by holding many parties and events, including presentations on wills, trusts and estates; geriatric care; and “the dietary need and nutrition of the mature person.”

Testimonies from the first wave of residents attested to the fine views of the trees, framed I imagine by their windowsills like a 19th century Currier and Ives hand-coloured lithograph. One resident said: “I am comforted my family knows I am secure and that there is excellent health service. I don’t want to be a burden on my children. I am too independent for that. Besides, I am so active, that Tacoma Pastures is really like a hotel for me.” The scaled down care free living offered by Tacoma Pastures was also matched by a certain moral view towards ageing. In the second issue of the Tacoma Pastures newsletter, some words regarding retirement read: “Maturity is a stage of life that has special significance. It is a time to put into effect a wisdom that is unattainable at any preceding age because you have attained perspective.” A certain amount of optimism sprinkled much of Tacoma Pastures’s early promotional materials. Photos of angelic nurses tucking in a perfectly manicured bed graced the pages of the Tacoma Pastures newsletter and brochures. Modern nursing care looked professional; an

¹¹ Quote taken from the Tacoma Pastures Newsletter, Fall 1972, Vol. 2 No. 3

¹² Quote taken from the Tacoma Pastures Newsletter, March 1973, Vol.2 No. 1

inviting comfort and a luxurious convenience emanated from those pictured rooms, where one could spot brightly coloured curtains, bedspreads and large windows with a sunny view. The optimism of it all also transpired in the way the marketing team offered residents the chance to move into bigger rooms if they so desired.

At the first annual meeting of the Tacoma Pastures residents' executive committee, the president of the Joint Church Manors board indicated for the first time that the sales results were less than satisfactory. Higher than expected construction costs exacerbated by the 1973 oil crisis, and the fact that Tacoma Pastures was only looking at a 40% occupancy, meant that Tacoma Pastures could not generate enough income to pay its increasing debt and facility costs. The economic crisis of the 1970s is not just a mere historical footnote, but a backdrop against which to situate the financial failings of Tacoma Pastures. Post-structuralists like Fredric Jameson and David Harvey have been making the argument that the 'cultural logic of late capitalism' ushered in a new dimension of global economic history. Historian Daniel T. Rodgers argues that in this milieu of post-Fordism, finance capitalism, global markets, and the destabilisation of 'identities', 'the age of fracture' is an historical period where, "Americans [were] trying to reimagine themselves and their society" (Rodgers 2011, 10). Rodgers goes on to say that in this age of fracture, "[...] older understandings of [the] social like in terms of institutions, solidarities, or the pressure of history could not help losing some of their force. Where instruments of finance came ever closer to Americans' lives—in pension stock funds, balloon-rate mortgages, leveraged buyouts, corporate restructurings, and plant closings—it was not surprising that the language of the market economics should travel with them, seeping into new terrains of social imaginations" (Rodgers 2011, 9).

After receiving the news of Tacoma Pastures's financial woes, the administration and residents decided to hire an extra sales counsellor. An 'opportunity lease' was offered, allowing prospective buyers to rent and occupy an apartment for a short period before buying a life lease. Tacoma Pastures residents also volunteered to act as tour guides, escorting prospective buyers around to see various furnished apartments, and other shopping points of interest such as the refreshment table.

Despite the vamped up efforts of the sales team and an ad hoc media blitz, on February 4, 1976 the Joint Church Manors board hired a lawyer and had a petition signed stating

their desire to effect a plan under Chapter XI of the US Bankruptcy Code. The board alleviated worried residents, who had just moved in less than two years prior, that the Chapter XI filing would stop the mortgage foreclosure and allow everyone time to work out a new financing plan. Letters were sent out in September of that year to every Joint Church Manors debentures holder with the subject heading: Mission Possible. The letter stated that given the unforeseen problems including adverse economic conditions, high real estate taxes, and slow fill-up, created a serious cash flow problem, resulting in Chapter XI proceedings. An appeal was made to debenture holders to forfeit and make a gift of their debentures. The board thought that if debenture debt were significantly reduced, a reformulation of a plan would be more likely. Several people responded and donated their debentures. Letters of thanks from the board read: "Not only have you made a wise investment, for we are on the edge of success, but you are making it possible to carry out what is a vital Christian mission, the proper housing and care of our retired." Despite the board's diligent efforts, it became clear that there were still not enough funds to rehabilitate the situation, and on February 4, 1977, the district court gave permission for a foreclosure. The lending bank acquired the title from Joint Church Manors and began looking for a new buyer. It was not until August 1979 that a final order issued by a district court judge cleared the path for a new board of directors to take ownership. A last-hour will amounting to \$200,000 helped to subsidise some of the increased costs, especially outstanding life leases. When the complications of the will were finally resolved, the court dismissed the Chapter XI case and dissolved the Joint Church Manors, Inc.

In the end, Tacoma Pastures was able to form a new board of directors and began operating as a not-for-profit retirement centre again. In order to convince the new financiers that their restructuring was sound, the board of directors decided to enlist the help of a Tennessee based company in 1978. The company offered many services including marketing, management consulting, administration, human resources, nursing care, and nutrition consultancy. Tacoma Pastures paid this company a monthly fee for managing the property under a three to five year contract.¹³ A few years later,

¹³ Another organisation in the early 1990s replaced this company. This Orlando, FL based company manages Tacoma Pastures today, and is the largest owner and operator of senior living communities in the United States. As of 2011, this company, which

Tacoma Pastures enlisted the services of a boutique investment bank located in Orlando, Florida to underwrite \$19.7 million worth of nonrated bonds. These bonds were used to advance refund an existing bond issue in order to generate cash flow earnings. These tax exempt bonds were sold to retail and institutional investors with yields of 5.25% to 5.32% and maturities ranging from 2026–2037, extending its previous 2019 senior bond maturity.

* * *

On July 14, 1983 the executive director of Tacoma Pastures announced plans for making extensive alterations to the third floor. One corridor on that floor was already designated and equipped for supervisory care. The new plan would be to make the entire floor entirely devoted to ‘personal care’ apartments. The renovations would also entail knocking down some pre-existing apartments in order to build a spacious dining room, an enlarged lounge and lobby as well as a closed centre for nurses and caregivers. These changes were motivated by Tacoma Pastures’s opinion that more of the residents throughout the main building required additional supervision and assistance, but not enough to need the services provided by the therapy and health centre. By consolidating these residents together, Tacoma Pastures could serve these residents in a more cost effective way. A second reason for the change was that Tacoma Pastures was losing prospective residents who could not live independently; there was no space to accommodate them with only one wing of the third floor dedicated to supervisory care already full.

In a Tacoma Pastures newsletter dated October 1983, the president of the residents’ association introduced personal care apartments as a new type of residency. The president of the residents’ association wrote that: “Personal care is indicative of the phased living concept our consultants advocate, that is where all levels of care are provided on a single campus, so residents may shift easily form one level of care to another as needed.” The newsletter went on to explain that: “The Tacoma Pastures campus will include the following phases of care: 1) Independent living apartments on

happened to be founded in 1978, operates over 570 senior retirement communities in the country. They have 35,000 staff and 55,000 residents.

floors 1, 2, 4, and 5; 2) Personal care apartments on the 3rd floor; 3) Health Centre will provide intermediate nursing and skilled nursing; 4) Small cottage-type condominiums for residents approaching retirement age.” Thus, the concept of the Continuing Care Retirement Community (CCRC) was officially adopted once the renovations were completed. The phased living concept along with consolidating those residents who needed extra help and assistance with the activities of daily living gave rise to an architecture of a segregated senior living model (see figures 1 and 2).

Figure 1 A rendition of Tacoma Pastures’s early construction site

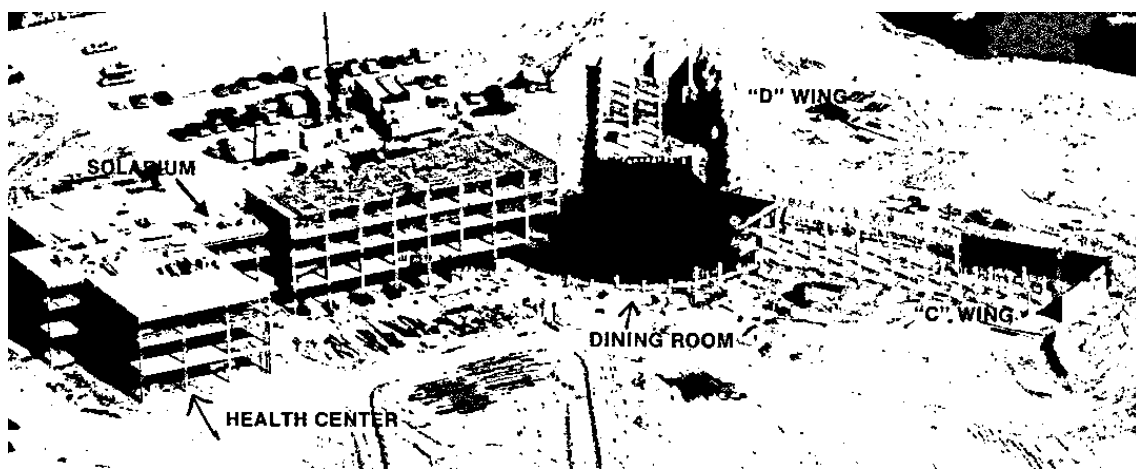
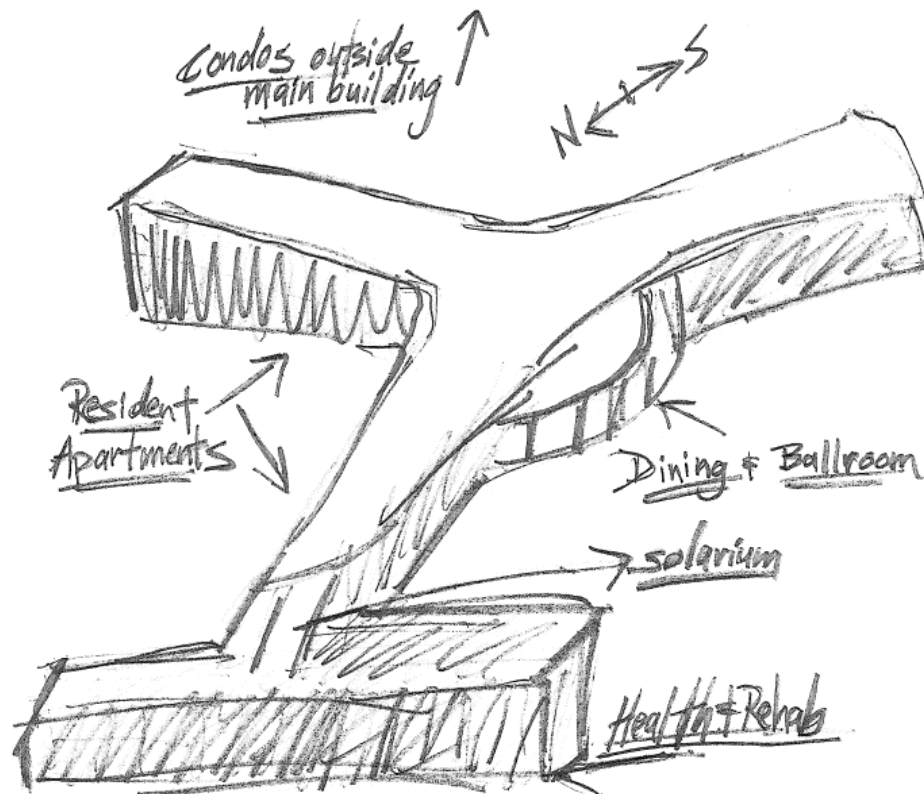


Figure 2 Sketch of Tacoma Pastures's main building



In addition to Tacoma Pastures's prior financial troubles, life in Tacoma Pastures was not without its problems. Ms. Phyllis Rapone, Tacoma Pastures's executive director, started off as a dietician when she came to Tacoma Pastures in 1981.¹⁴ When she first arrived, the resident committee (referred to later on as the resident association) was in her words "very strong." She said: "The council members of the association were the overseers; they ran the operations and made all the decisions regarding the food and the activities without really getting everyone's input." She attributed their uncontested power to the fact that most of them came from positions of local power and influence. They were an independent body; Phyllis remarked that: "You had to be in that social circle and have the right name to be in the association." Phyllis started working at Tacoma Pastures when those in power, ex-board members of the Joint Church Manors and resident association officers, really started to age. They were pushing eighty years old, and no one dared to say anything to them about ageing. Phyllis also stated that the staff members who were working in the dining rooms had no management experience let alone any background in nutritional science. She said: "Things were a lot more

¹⁴ I interviewed Phyllis Rapone on July 14, 2011.

chaotic back then.” I was told too that people who had a wheelchair or needed a walker did not go into the formal dining room, which was given the name ‘The Scenic Dining Room’ for its views overlooking the wooded area outside the windows. Furthermore, Phyllis said that even though people came from an interdenominational Protestant church in town, very little was said of religion in public. Tacoma Pastures started off as a Christian endeavour, but it had to welcome people from different faiths in order to meet its occupancy requirements.

Phyllis continued: “And now you had to talk to them about aging, there weren’t any interventions, no surgeries; you didn’t rehab someone at 70-plus. The group in power started aging, so the evolution started with them. They started to become frail.” She recalled an instance where a prominent politician in the area, upon entering Tacoma Pastures in the early 1980s did not want walkers in the scenic view dining room; yet he had a walker himself! From talking to Phyllis, one gets the sense that there was a tremendous fear of ageing. The residents did not talk about it, and Phyllis told me that back then if you happened to slip and fall, you didn’t let anyone know, not even your spouse. Phyllis tried to change that stigma and atmosphere of fear, but she said it was hard, and the fear was so entrenched. Additionally, if someone had dementia back then everyone including the staff would pretend that nothing was wrong. There was no offer to take them to speech therapy. Needless to say, Aricept and Exelon medicine patches were not available back then.

The health centre attached to the main building was a place designed for providing nursing care, but it was understood that those who went there never made it back to the main building. Phyllis recounted several incidents whereby people who moved to the health centre lost all contact with their friends and acquaintances in the main building. The health centre was the final stop, the place to go to die. People were afraid of the health centre and rarely did they visit unless they had to. Our interview concluded with Phyllis saying that: “Before people would often use the word failing and declining. Today, we know better and say you’re simply aging, and so what I say to our residents is we will all be dealing with it. So how can I help you with the process?”

Even though things have since changed, other things have remained the same. According to the official 2010 United States census, the city where Tacoma Pastures is

located has 48,659 people compared to 47,540 in 1970. The main structure of the building has not changed much, but there have been a host of additions and renovations. Since Tacoma Pastures' only licensed SNF (the former health centre) is a small (albeit expanding) section in the back of the complex, the majority of Tacoma Pastures residents still have to go to the city hospital for major operations, emergencies, and even regular check-ups. The city is less than 10 miles away, and has seen its share of hard times. Tacoma Pastures was once predominantly white and middle class, but since the area's nearly two and a half decade long economic depression, its demographics have been changing significantly. Working class residents are now bringing in Medicaid and Medicare dollars to purchase modified contracts and pay-for-service arrangements at Tacoma Pastures.

The former health centre, which was attached to the northwest wing of the Y-shaped main building, received funds in the late 1990s for a 9000 square foot expansion. It is now called the Centre for Health and Rehabilitation (CHR). Today, Tacoma Pastures is a CCRC and consists of seventy-four Independent Living apartments, seventy-seven Independent Living Plus units, forty-five Memory Care units, and one hundred and fifty skilled nursing beds in the CHR. There are roughly three hundred residents, and four hundred and sixty people are on Tacoma Pastures's payroll. Tacoma Pastures also has just over forty condominiums, which are collectively referred to as the Tacoma Pastures Clusters. According to Tacoma Pastures's promotional materials, the Clusters provide Condo Living for the "active retiree", and can be purchased by anyone over age 55. People who choose to purchase these condos own the units, but Tacoma Pastures maintains ownership of the property (land) and provides external maintenance, like shovelling the snow and basic landscaping. Furthermore, condo residents have access to the gym, dining facilities and other recreational events housed at the main building. The smallest condos are about 1,200 square feet in size; a recent 1,539 square foot three bedroom and two-bath condo sold for \$210,000.

Studio apartments still make up the bulk of the Independent Plus 4th floor and the Independent Living 5th floor. Even though there is no dining room on the 5th floor, residents who do not wish to take the elevator down to the second floor to eat often come down to the dining room on the fourth floor. The third floor in the main building is now separated into three enclosed corridors dedicated to Memory Care. Each wing on

the third floor is electronically locked and referred to as a 'neighbourhood' taking its respective names from local rivers. Each neighbourhood has its own living space and dining room. The river neighbourhoods are devoted to those residents with dementia and Alzheimer's. The second floor of the main building serves as the main public space, where visitors come to sign in and wait for their loved ones. Additionally, the formal dining room is also located on the second floor just steps away from the entrance. The second floor also has two hallways devoted to studio apartments designated Independent Living. One of these halls leads out to the garden, which features an impressive pond and waterfall, courtesy of a \$25,000 donation. Meeting rooms, the kitchen for the formal dining room, the director's office, and the mailroom are also located in this third hallway, which leads past the solarium to the CHR. Because the main building is perched on a hill, the CHR is located further down the hill and has only three levels. The bottom level of the CHR can be reached through the floor of the main building just past the Alzada Penderson Ballroom and down the hall from the beauty salon and exercise room. Walking past a set of electronically secured doors one spots an 8 ft. high birdcage with finches. Past this and through another set of electronically locked doors is the CHR, which because of its SNF license operates more like a hospital. Even though the resident centre and the CHR both belong to Tacoma Pastures, they are run by two different directors and have a completely different staff of caregivers and nurses. The first floor has small corridors for people who are intending to stay short term; the people here are mostly recovering from surgery or have medical conditions that require specialised nursing.

On the first floor of the CHR, there are also offices for nurses and social workers along with the rehabilitation centre (a gym replete with rehabilitation and medical equipment) and another dining room. Past the dining room is another entrance to Tacoma Pastures used mainly by the ambulance to take people in and out of the CHR and the resident centre. This entrance is situated on the back end of Tacoma Pastures allowing for ambulances to transfer the recently deceased in black bags in a less conspicuous way. The second and third floors of the CHR have two hallways devoted to skilled nursing. In the CHR, two people usually share a room. The second floor of the CHR is known to have residents who are capable of wheeling themselves around, and

therefore there are two dining rooms to choose from. On the third floor, there is only one dining room.

In 2010, \$1 million was raised to finance a renovation of the main building. Renovations included: 1) A new covered entrance with heated pavements outside the entrance; 2) Converting more rooms for Memory Care, and 3) Expanding some Independent Living apartments to include kitchens, laundry facilities and private patios. Furthermore, another \$3.5 million is being raised to add 14,000 square feet to the CHR, which now boasts a marketing slogan that reads, "Getting you back where you belong." The CHR is scheduled to have one hundred and thirty-three beds for its "short term, post-acute and long-term care facility."

Chapter 2: The Accidental Caregiver

My fieldwork started when I began volunteering at Tacoma Pastures. After contacting the director and risk manager of the CCRC, and informing them of my interest to conduct participant observation, they suggested I work with the recreation department as a volunteer.¹⁵ During my initial fieldwork period, the recreation department, which incidentally changed its name this year to 'recreational therapy', was in charge of organising all the social events and activities at Tacoma Pastures. These activities included afternoon movie screenings, local sightseeing and shopping trips, sing-alongs, bingo, holiday-themed parties, vespers, 'news bytes', music with Lucy (the resident piano player), 'reminiscing hour,' 'sensory group' (hitting a balloon around while seated in a circle formation), knitting/crochet hour, 'memory tea,' 'mind builders' (Sudoku and crossword puzzles-US presidents and the bible edition), popcorn social, etc. In addition to organising various events and informal gatherings throughout the day (usually before dinner and in between occupational/speech therapy sessions), the recreation department also conducted one-on-one visits with various residents. Many of the residents in the health and rehabilitation section of Tacoma Pastures were either bedridden or too sick to participate in the group activities. Because of this, the recreation department kept a file for each resident, ensuring that these residents were monitored for their 'social health.' A Tacoma Pastures's social worker also worked alongside the recreation department to assess and customise various recreational activities for these residents. For example, one resident who had recently suffered from a stroke, and was left slightly paralyzed and with mild cognitive impairment, was assigned two women volunteers from the recreation staff. Because the resident in question was an amateur painter before her stroke, it was felt that she should be given a chance to read and browse through a collection of art books. Needless to say, no staff member or volunteer could get her interested in reading about art; she loved to paint,

¹⁵ I sent a letter to the director and risk manager explaining my interest to conduct research on ageing and social life at a CCRC. This was followed up by a meeting in which I was granted permission to study the experience of residents and caregivers at Tacoma Pastures. In addition to this, it was mutually decided that I would be a good person to also document and write a brief historical account of Tacoma Pastures for 'institutional memory' and marketing purposes.

and no book could offer her any substitute. As the weeks passed, I came to sit with her and wheeled her around the campus for short jaunts. The recreation department assigned and scheduled volunteers to particular residents based on an initial assessment of personality fit, interests and gender.

As a volunteer, I worked with two middle-aged women volunteers, and two high-school students who spent a few hours on Sunday afternoons visiting residents and playing bingo. I wanted to get acquainted with the CCRC fairly quickly and spent about six hours everyday during the initial phase of my fieldwork research at Tacoma Pastures. The recreation team consisted of four fulltime staff members, including a recreation department director in charge of work schedules and other administrative tasks. During the time I was at Tacoma Pastures no one in the recreation department held any professional certifications. Three of the four staff members were college educated; one of the more charismatic members of the recreation team did not possess a college degree.¹⁶

Not only did I spend time visiting the health and rehabilitation centre residents in their rooms and talking with them on such topics as the weather, how they were feeling that day, their views on the food at Tacoma Pastures, and various TV programmes, I also accompanied residents outside for short walks. For residents in wheelchairs who wanted to smoke, I brought them outside to the designated smoking section, and helped them put on their mandatory fireproof white bibs. Some of my other chores included helping the recreation team set up various events and parties. At first, I was in charge of setting up the CD and video player for music and movie hours. Later on, I was allowed to run small events and activities on my own, freeing up some time for the recreation staff to get to some of their neglected paperwork. Before long, I assumed the position of calling bingo twice a week. Other tasks which I did as a volunteer included going from room to room to get people interested in attending the various events, and transferring people to and from these events. Because volunteers are not allowed to physically

¹⁶ Just one month after I left the field, I found out that Mariam, a recreation staff member, was let go after five years of service, because they were hiring a new staff manager to head up the revamped Recreational Therapy section. This new hire was a Certified Therapeutic Recreation Specialist (CTRS). She led the rest of the team, and everyone soon acquired similar certifications. Today, Tacoma Pastures boasts of having three fulltime CTRS recreational therapists.

transfer residents out of beds and their chairs, most of my interaction involved helping residents with their wheelchairs and foot-pedals. As a volunteer I was not allowed to touch or make their beds. I was also strictly forbidden from helping them eat during meal times. The residents in the health and rehabilitation centre viewed me as a friendly young person, who was in their eyes not going to be a permanent fixture of the place. For the time being, I was someone they could engage with superficially. Many of the residents talked to me about their sons and daughters, especially if they were deemed successful. One resident let it be known to me early on, that her daughter had just been promoted in the local police force. Although I was not part of the care system as such, the caregivers in the health and rehabilitation section commented to me on more than one occasion that what I was doing, volunteering and studying old people and care, was something 'nice' and 'probably valuable for society'. As long as I did not get in the way of their professional care, I was more than welcome to hang about, and even to talk to the caregivers. If I was in a resident's room while a caregiver had to come in and take the resident to the toilet or to administer medicine, it was assumed that I would gracefully depart and not ask too many questions. Additionally, if I was sitting with a resident during a meal, it was expected of me not to question or interfere with any resident's diet, and their eating habits and preferences. This was deemed a medical issue, and not a concern of the volunteer.

Some of the other tasks I performed while I was a volunteer included helping a woman resident order clothes from a mail order company. On several occasions, I brought clean bed sheets and bed spreads for the residents. In the afternoons, I made coffee and delivered coffee to residents who could not make it to the dining room. Some of the residents really enjoyed it when I wheeled them downstairs to the ground level of the CCRC to take a look around at the small confectionary store named 'Stop N' Shop.' I kept residents company during meal times and attended monthly resident council meetings with some of the residents as well. When family members came to visit, which was rather seldom in the health and rehabilitation centre, I would talk to them about the weekly planned recreation activities, and about how their loved ones were doing in a rather cursory way. Over the course of just a few weeks, my chores expanded to include taking residents to the front of the CCRC so that they could then be transported by the Tacoma Pastures transportation services to various medical appointments in town. I

soon learned who needed to take an extra sweater or jacket on these trips, and participated with the residents in some of the activities when other staff members were organising them. With the residents who suffered from dementia, I was tasked to look after them, especially after the end of a group activity, to make sure that they did not stray before a caregiver could return them to their rooms. I blew toy soap bubbles, and tried to sing in harmony with many of the residents who participated in the activities scripted in each month's 'recreation calendar.'

Although I have just given a list of tasks a typical volunteer undertakes at Tacoma Pastures, I witnessed and participated in other matters. For one thing, I began taking notice of how the residents started to act around me, and especially in front of others. In the beginning, the residents were kind and courteous enough to put up with my presence, but after a few weeks had gone by, they began to employ me as a reference point in their daily discussions. Some of the residents would take it upon themselves to show me around, as if it was their job as a host to introduce me to the rest of the community. I was someone they could interact with. Others confided in me, by expressing their annoyance at fellow residents (sometimes their own roommates). One resident complained to me that her roommate was selfish and all that she ever cared about or talked about was herself. This resident sought me out rather than a caregiver to acknowledge and confirm her opinions. I observed caregivers and residents, and how they interacted with each other. Even though a significant portion of my time as a volunteer was spent in the health and rehabilitation centre, I ventured out with many of the recreation staff members to the rest of the sections in Tacoma Pastures including Memory Care.¹⁷ As a volunteer and a researcher, I listened, observed, and tried to make myself as useful and sociable as possible.

Being a volunteer at the beginning of my fieldwork gave me a great introduction to my field site. I started developing an easy-going relationship with several residents and staff members. It also gave me access to various sections of Tacoma Pastures, beyond just the health and rehabilitation centre. I assisted the recreation team with residents

¹⁷ The reason I was first put in the Health and Rehabilitation Centre as a volunteer was because according to the social worker, the residents there were the most depressed and loneliest. Over the course of my fieldwork, I witnessed that the Health and Rehabilitation Centre had the least number and frequency of family visitors.

on the third floor in Memory Care, and I also interacted with residents from other floors, especially when I was taking them to various events and parties held in the lower level ballroom. As a volunteer, I had time and the freedom to simply observe the residents, without having to react to them or to risk being seen as not doing my job as a caregiver. The role of the volunteer functioned for me as an initial point of reference for which to measure and make sense of the work caregivers actually performed and what I thought constituted caregiving from the outset; it brought into relief what separated caregiving work from volunteerism (and what was not carework). More than this, it gave me the opportunity and a moral space to see and reflect on ageing. The rest of this chapter will go into this distinction more, but first of all, I will present some ethnographic material. I will examine in detail how I came to be introduced to Ryan, a resident in the health and rehabilitation centre, and how my time with him and the recreation department evoked specific ideas of social relations, empathy, and the nature of living with uncertainty in a SNF context.

* * *

On my first official day as a volunteer, I arrived at Tacoma Pastures at nine o'clock in the cold morning. I met with Nathan, a staff member of the recreation department, who just interviewed me a week ago for the volunteer position. The other recreation staff members were just getting in, throwing their bags and coats on their desks. Nathan wanted me to do some data entry, which involved organising a database on resident transportation requests. Residents who do not have cars or family members nearby, can ask the staff to take them to various non-medical trips, including the movies, shopping, nature parks, etc. A form had to be filled out a month in advance, and it was my job to consolidate all the requests, which were already two months behind schedule. About an hour into my data entry, Nathan took me down the hall to see Ellen. Ellen, the recreation manager, had a different office, which was larger and more 'corporate' like. She had newer office furniture, a much larger desk, two computers, and shared her space with the marketing staff of Tacoma Pastures. I spoke to Ellen, and she immediately wanted to know if I had travelled anywhere interesting lately, and if I would be willing to make a 'destinations' slide show presentation for the residents sometime later in the month. I told her I had some great pictures and stories from my recent trip to Taiwan, and that I

would be more than happy to present my vacation. After returning back to the recreation staff office, Nathan told me to wait for Tim, the Tacoma Pastures transportation director and bus driver. Tim was supposed to show me how he wanted the database to be set up, but when he finally came around to my desk a half hour late, he displayed very little interest and knowledge of the database system that was apparently already in use. I noticed that Tim was wearing a small cell phone earpiece, and sported an earring in the other ear. After half an hour or so of my work on the desktop computer, Nathan took me through a set of double doors that were being disarmed by someone I took to be a caregiver, dressed in a dark blue set of nursing smocks.

Nathan told me that he would offer to take me around the health and rehabilitation centre to get me acquainted with the staff and the layout. As we were walking past the rehabilitation gym, where I was able to sneak a peak of some of the equipment including neoprene dumbbells, medicine balls, stretch cords and treadmill machines, another recreation staff member was hastily walking towards the elevator. Nathan introduced me to Gary; he said hello and informed me that he was getting ready for his residents. I asked him what was in his clear plastic container. He told me that they were materials and flash cards for his 'Cranium Crunches' session with the residents on the second floor of the health and rehabilitation centre. As Nathan took me down to the living quarters of the health and rehabilitation centre, I saw two middle-aged women caregivers, and residents in their wheelchairs positioned randomly on both sides of the corridor. I tried not to stare, but I was aware that these residents were also looking at me. They seemed half-asleep, like cats with one eye half open. I remembered feeling that the residents were watchful, and that I could feel their gaze more than they could probably feel mine. I felt heaviness walking past each resident. At this point, I also began to question my own presence in this hospital-like section of Tacoma Pastures. From one of my days of fieldwork, I wrote in my notes:

"Is my presence here a productive/reflexive problem? What is my role as a volunteer? Is this trivial because I am not paid, and do not provide any real services? Isn't companionship more important? And if so, why is this left to just volunteers? What can I do as a volunteer? What is my role and what is the price of my intervention?"

On the second day, Nathan took me around to visit some of the other areas in Tacoma Pastures. He showed me the reading library (which had two newspaper subscriptions), the ballroom, and introduced me to the two women who worked at the beauty salon. Nathan and I spent the rest of the morning moving long tables and chairs in order to set up for an evening event. Nathan then took me to the accounts office to sign up for lunch. He paid for me that day, and I took a printed slip of paper and checked off in pen what I wanted for lunch from a list of choices. When lunchtime came, which was around 12:15 p.m., I headed into the kitchen on the main level, and grabbed a tray. I was directed to fetch my drink and dessert from an industrial size refrigerator. I found the selection of juices that were already poured out in styrofoam cups and covered with a thin saran wrap. After grabbing some cutlery, I headed to the food counter, and an Eastern European woman and another man with a tiger tattoo covering his entire left forearm served me my hot meal. I took my food, and found Nathan eating his lunch with a few of the residents on the second floor of the health and rehabilitation centre. I pulled a chair from an adjacent table and joined the four-top. Next to us, a few of the caregivers from the health and rehabilitation centre along with some of the food servers (hospitality staff members) were sitting down and having their lunch. All the residents were given their food and drinks, and now the staff could take a few minutes for themselves. I noticed that the two African caregivers were talking to one of the Eastern European food servers about taxes, and joking around that they should be given more food discounts at Tacoma Pastures. The food server jokingly remarked he would consider it only if the caregivers would give him a discount when he got old and needed their care. I turned to one of the residents on my table and asked him if it was easy to make friends. I said it seems people are used to each other and friendly around here. He said, "Sure, it's easy to make friends here, even if a new person comes along like yourself. We just ask 'em, what's your name?"

The recreation staff members attend to residents in a very particular way. They often say regarding their activities and visits, "We are the life of the party. We bring the party." Eddie, whose mother (Hawaiian) and father (Swedish) met during World War II, said that before he started working at Tacoma Pastures, he went to Hawaii back in the 1990s to work as a gold crown denture maker. He was eventually sacked after six years, and decided to move back to the area because of the lack of jobs and the increasing cost

of living in Hawaii. I asked him following his comment on the party, why he was always smiling and joking so up front with all the residents. Eddie often joked with a woman resident who had lost her hair some time ago. They got on well, and their banter took on a rather personal note. They exchanged swipes at each other, and asked sarcastically of each other, are you sure you're alright? To this the woman would often say, "Well I'm not doing as well as you, for one thing I'm wearing a wig." Eddie said to me, "It's sad to see people in the dining room hunched over, and can't eat. But I can't dwell on it. I have to get my job done." Macy, the other recreation staff member chimed as well, "That's why we laugh and have a good time and say stupid things to one another, cause this place is sad."

One day, I wanted to eat lunch in the recreation staff room, but Nathan advised against it. He said, "We typically don't take our breaks in here. Lunch is our non-professional thirty minutes. This is after all a work space, and we may say something unprofessional." The conversations that typically took place in the recreation staff room were very much about particular residents. It was not uncommon for the staff to go through a checklist of residents. They took turns commenting on how they thought each resident was doing. More specifically, I took down the following conversation just one hour before lunch:

"Why do I like her? Because she is sweet. We should get her some other kind of painting, cause she used to be really good, but now she doesn't have the ability and that might frustrate her more. We have to think about some creative substitutes." After Macy said this, Eddie asked, "How's Trish doing?" Nathan replied, "Same old, same old. She's independent. What about Reynolds?" Eddie said, "He's no problem; he's fine. But John is another story. He still doesn't wanna do anything. I think he needs more one-on-one or sensory work. We need to get him out more and work on his communication."

Eddie turned to Macy and asked her about Cathy. Macy responded, "Cathy slashes and dominates group activities. She shouts and is more confused." I noticed that some of the residents on their clipboard were highlighted, and I asked them if this was because they were 'behavioural problems'? Macy said, "No. It just means that these people have Medicaid." Macy continued on talking about Cathy and how she refused to socialise with others. The discussion shifted to another woman resident. Nathan explained to us that

Jennifer was doing so-so. He said, “Jennifer’s got good days and bad days. Some days she is very passive. Her husband comes to visit, but her responses are getting delayed. It’s almost like she’s in zombie mode. We have to keep an eye on her. I might even request changing her care plan.”

It seemed to me that their exchange evoked a kind of gossip, despite the fact that they were formally assessing the residents who were specially assigned to the recreation department for their therapy services. Even as they were talking about these residents, the staff members had a very sincere and concerned tone and look in their faces. They were not mocking them, but their terms of reference and referring to certain residents as ‘an emotional snap’ seemed to be particular. At one point, Eddie even asked me about Ryan, and I told him, “He shows me around the place. I think he feels good about this and he is engaged. We take strolls down the hall and he always says to me “what’s good today” or “heard anything good today?”

I asked Eddie about how he knew whether or not someone was doing well. He told me that if people are doing better, like Tom for instance, you could see it. He said, “Tom used to be in bed like 99% time, now he is out of the room more.” He then told me and the rest of the staff members to remind the residents that they have rights and to show them the survey books and the informational materials on the bulletin board regarding residents’ rights and information on how to contact the Tacoma Pastures’s Ombudsman. He said this was important, because when the state government guys come to do the surveys, and ask the residents about whether or not they are aware of their rights, most of them act clueless and this gives us a bad inspection report.

Nathan encouraged me to familiarise myself with the various resident profiles and files they kept in the office folders. He said that this would help me with my one-on-one visits, and that getting to know the residents was very important. I read through some of the profiles, which included such information as resident hobbies, ‘likes’ (e.g. food, sports teams, ice cream flavours), and a discussion of various activities. Some of the files mentioned the need to encourage residents to make friends. One of the files noted that a resident was going through depression because her daughter was sick. Other information I gleamed from the files, which were really evaluation reports, included such advice as, ‘Take her for more walks’, and ‘Read to her, she likes that.’ As I finished

reading the files, I returned the files to Macy's desk, but not before seeing two small plaques she had framed on top of her computer. The first plaque read, 'Immature Love: I love you cause I need you/Mature Love: I need you cause I love you.' The other one read: 'People put up walls not to keep people out but to see who cares enough to break 'em down.'

In another episode, Macy said to Harry, an African-American resident in the health and rehabilitation centre who suffered a speech impediment from a recent stroke, "We want you to be more active so that you feel better. What groups would you like to be in or things you wanna do?" Macy was sitting next to someone who looked to be like an auditor for the state or a contract worker. This woman said to Harry, "I will work with you two days a week. Is this okay?" Harry acknowledged what she was saying, and only nodded gently and somewhat reluctantly with his eyes. This other woman, who was dressed in a business suit, was actually conducting some kind of medical state survey. She was busy typing on a laptop, while she was talking to Harry. She looked up from her typing and said to Harry, "We want to see you get initiated in things. To be active." Macy left the room, and I remained there sitting at the table with another resident while the survey woman pulled back from her laptop and stood rather abruptly. As she got up and left, she looked back again, and walked towards Harry wheeling him out of the sun. She said, "Oops, I didn't even realise you were in the sun."

In addition to my time in the health and rehabilitation centre, I also spent a little time volunteering on the third floor, where many of the residents with dementia and Alzheimer's lived. About two months into my fieldwork, Nathan took me up to the third floor, also known in Tacoma Pastures as Memory Care, to visit some of the residents. We headed down one corridor, but we could not locate any of the caregivers. All of the residents were in their rooms, but Nathan thought we needed to find Jared first, the other recreation staff member who worked exclusively with Memory Care residents. We headed down another corridor and peered through the security locked double doors. Jared was already in there, and I joined him. Jared introduced me to some of the residents who were sitting in the common living area. The television was on, but no one was watching. I talked to four women and remembered thinking that they were very friendly, and quite sharp. I did not know what to expect, because this was my first time encountering anyone diagnosed with Alzheimer's. The residents kept asking me where I

was from, even though I had just answered them two minutes ago. I remembered feeling guilty as well for trying to make sense of their dementia. I quizzed them on where they were from, and then asked each of them where they thought the person sitting next to them was from.

The next day, Jared said he needed some help and so I went up to the third floor. I stood in front of the double doors and knocked; no one had given me the door code yet. Jared opened the door and told me the code, but not before teaching me how to cover my hands when entering it. He said, "We just changed the codes. We have to be careful, because some of the residents have taken notice of the codes. Some of them are real escape artists." He began talking to me about the residents. He informed me that in order to get Donna to participate in anything, her neighbour Tammy would have to be involved. She only did something if Tammy did it as well. It seemed to me that Jared had quite a lot of information about the residents in Memory Care. When I asked him about a particular mechanical device that I was unsure of, Jared remarked, "That's for weighing people without taking them out of their wheelchairs. You weigh the wheelchair separately. Take notice of that once and for all, and then its simple subtraction." He even went further to say, "The caregivers do the weighing, and this happens once a month. This ensures that the residents with dementia are not undernourished. They can forget to eat you know. So we regulate their diets as well. It's not that people in Memory Care are the only ones with dementia. Many others in Tacoma Pastures have it. It's just that these people have it more. And so you learn about their needs. If you get the chance to transfer one, you'll see just how light they are. Many of them forget to eat and you can feel it in their bones when you lift them out of the chair."

We went to see if Abby was in his room; I was supposed to visit this resident. When we arrived at his room, Abby was asleep, and I suggested that perhaps we should come back. Jared said no, and that we should wake him up, and perhaps read some poetry to him. I asked him again whether or not we should disturb him. Jared replied, "These people are in bed all day. It's our [the recreation department's] job to wake 'em up."¹⁸

¹⁸ The idea of getting (and keeping residents during the day) out of bed stems from the idea that residents should be engaged with others and working on sensorial stimulation. The phrase, "use it or lose it" is sometimes uttered by members of the recreation

Abby suffered from severe dementia, and at first I didn't know how to even communicate with him. His sentence patterns and references were erratic and all over the place. Jared said to me later on, "Don't worry about conveying any message to him. Just get him to mumble and talk. As long as he's using energy, that will keep him alive."

When I first interacted with the residents in Memory Care, I recalled thinking to myself how can I even do fieldwork with 'these people'. The caregivers don't seem to have any meaningful conversations with the residents. There is just so much silence, mumbling and sitting in front of the television. When I was talking to Abby he could not answer the simplest questions about the time of day or when dinner was. Abby pointed to the lamp, and said it was trying to tell me something.

Jared from the recreation department spent all of his time with the Memory Care residents in the afternoon. He was a fan of Perry Como, and during music appreciation hour, he often played music that he thought was reminiscent for the residents. Most of them did not care for his music selection, but when it came to playing Christmas music, even when it was springtime, the residents would happily sing along to every song, word for word. The residents also talked a lot about the weather. The windows in the common living room area in memory Care were larger than the windows in the other common areas of Tacoma Pastures. Many of the residents commented that the weather looked awful outside, and that in a sense they were glad to be inside where it was safe.

Changing topics, the balloon game was a well-liked activity. Residents sat in a circle in the common living area. Once they were in position, Jared would tap a large bouncy balloon in someone's direction. The residents in Memory Care loved this 'game', because it gave them the opportunity to laugh at people's reactions, especially when a soft balloon hit someone square on the head. They commented on each other's bounces and throws, and waved their hands in eager anticipation for the balloon. One of the residents announced, "Oh my head!" when the balloon struck his head. Everyone, including him, laughed. On one occasion, Jared even had me play some disco music from the computer to accompany our game of bouncing the balloon around. The residents enjoyed the game, because a little flick of the foot or a small touch, could produce a large

department as a way to acknowledge, even if superficially and occasionally, that lying in bed may accentuate debilitation and enfeeblement.

affect; the balloon could be launched across the room, and everyone could be brought to laugh simultaneously.

On one snowy late afternoon, I sat with some of the residents in the dining room of the health and rehabilitation centre. Stacey was at my dinner table, and talked about her daughter. She told me, again, that her daughter was a retired army soldier who was smart and had great marksmanship. Stacey claimed that her daughter won all kinds of shooting competitions. She said, "My daughter's now in the local police force, and she's a real minority. She's white and plays basketball for the team. You know most of the team members are black." I noticed that Stacey always smiled and flapped her hand around to draw attention to her points whenever she talked about her daughter. Gwen, who is Stacey's roommate and who complains incessantly about the little black bugs that are overpopulating their room because of Stacey's potted plants, started talking about pill pushers. She called the medical technicians (med tech) pill pushers, and said to everyone at the table, "Look at them in their corner office. They are outsiders. They tell me I got to take eight pills but I don't know what any of them are for." Soon after, a nurse came by to start handing out people's various medications at the dining table. Gwen said to the nurse, "Hey, we were just talking about you and the pill pushers." Stacey laughed and I grinned; I think the nurse blushed.

Gwen was not feeling well that day. Her daughter, who had never smoked, just suffered from a collapsed lung and was now in a hospital two hours away. Gwen was uneasy and depressed, and wanted to go back to her room right after dinner. Stacey who knew about the situation, said, "No, you stay with me (as if to imply that she would look after her at the table)." Gwen didn't leave the dining room, but wheeled herself to the end of the dining room and stared outside the window, looking at the six-inch snow covering everything. On another occasion, Stacey confronted a caregiver and asked why Gwen was not given a shower. Stacey told the caregiver that Gwen was upset because of this. The caregiver turned to Stacey and said, "That's not any of your concern." Stacey responded, "Of course it is, she's my roommate."

Everyone left dinner, and I had to take another resident downstairs to hear someone playing ragtime music on the piano. I saw some people half asleep, while others were rocking gently in their chairs and smiling. At the same time people were hacking up

coughs, and workers were gathering their belongings for the end of the day's shift. I came back up to the dining room in the health and rehabilitation centre, and found Gwen, still alone, staring out of the window into the coming darkness.

Ryan

On another day, I showed up promptly at 9 o'clock in the morning. I met Deena, the social worker, who was going to hand me some instructions. She introduced herself, and offered me a comforting smile. Three other residents were leaning in their wheelchairs, half-watching the morning news, as we started heading towards her office. Deena closed the door behind us and said, "Ryan will be thrilled to get a male visitor. He wasn't too interested in the past one. Just so you know, he's had a stroke and is beginning to display some vascular dementia. You can keep him company, and this may help his dementia from getting worse."

When I first approached Ryan's room, which of course was all the way at the end of the corridor—as these things usually are and not just in the movies—I didn't know what to expect. We ran into a nurse who looked at Deena and asked if she could be of assistance. Without saying anything, Deena mouthed the word (Ryan) and the nurse understood the nature of our visit. I entered the room and took notice of the bricolage ensemble before me. There were the usual suspects: a TV remote duct taped together, medicine pills next to a small paper bowl of butterscotch pudding, newspaper clippings, an incomplete set of used poker cards, and a teal coloured plastic dysphagia cup for the successful completion of swallowing. I walked toward Ryan without maintaining direct eye contact; I was shy, or perhaps I felt that we should both be rather coy in our initial encounter. Deena said to Ryan, "I'd like to introduce Phil. He's here to hang out with you and to learn a thing or two from his elders. Would you mind it if he spent some time with you?" Ryan said, "Well, I suppose so. I don't see any harm in that." And so Deena left us to our own devices.

Ryan had nice thin whitish hair, which was brushed to the right side of his head. I noticed that his cheekbone on the right side of his face was indented, and that he had a few neck warts, and was missing some front teeth. The room was nothing special, and

reminded me of a 1960s hospital room, the ones with the heaters that go on banging and thumping well into the night. I took notice of a black and white wall calendar, which featured pictures of his family. Next to the calendar was a taped up Xerox photo of Ryan in his late teens, and his brother in an army uniform. I decided to initiate the conversation by asking him how he was doing. Ryan said, "Well, you see they got me here learning new things." I saw two popular fiction books on his windowsill, but didn't spot anything else that might indicate what this learning was about. I asked him, "How long have you been here?" He replied, "Two years." "So, what kinds of things have you been learning?" Ryan pointed to a polished wooden slide next to the dresser and said "I've learned how to get myself from the bed to the wheelchair and back." I saw that he shared a room with someone and so I asked him if his roommate was around. Ryan said, "He's getting tested or something. You can never know when people are doing good, they may seem to be doing good, but sometimes they aren't." When I asked him how he liked it here, he said, "I'd do things differently. I am not here to critique. Besides I have no authority."

At this point I noticed that he had trouble keeping his very swollen and large right foot on the foot pedal. It kept slipping off. There was a white sock with his name on it over this enormous and crooked foot. But Ryan insisted, that it was the swelling on his other foot, the toes on the left foot, that needed to be elevated and that this was his main problem. I told him that I was a volunteer, and that in addition to meeting new people, I was an anthropologist researching the experience of ageing and caregiving. Ryan responded by saying, looking at his foot, "It will take ten years to heal." He said he was here to get better and that his family, including his wife who continues to live in their old house, supported *his* choice. According to Ryan, "My wife, cats and dog are at home. She comes to visit, but I really need to get better so I can shed the minimum. I am here to protect my family." A brief silence ensued, and Ryan said, "Lets see. What else should I tell you..." Ryan launched into a sort of family history with me, and without my provoking. Ryan told me of his job with a local tubing company, and how he used to make steel tubes and strips. He also made it a point to say that he was married before he went to college, and that when he first started working, people around him did not have any money or 'the right position' to help him. He became a factory director until the day his company was bought out by a larger multinational company. I learned from him that

his parents were born in Poland. Ryan's father and grandfather moved to Pittsburgh to work in a furniture store. His grandfather wanted to go back to Poland, but his father eventually stayed, and his mother moved to America. Many years later, his father died in a car accident, and Ryan was left to look after his mother. Ryan said that his mother lived to eighty, and that she had a car and was very capable to do things up until the end. He told me about his son and wife who lived not more than ten miles away from Tacoma Pastures.

Over the next few weeks, I spent most of my time with Ryan. I visited him first thing in the morning, and throughout the day, I took him with me to various activities and events run by the recreation department. In addition to talking to him about his family, the news, my family, and about me bringing him some more smokes (which I never did), he wanted me to assist him with a few projects. One of the projects he wanted assistance with was trying to get his wheelchair and foot pedals adjusted. Because of his foot, and the fact that his pedals were old and needed to be realigned, I took him one day to find Joe, the Tacoma Pastures occupational therapist and mechanic. Ryan wanted me to come with him; he said that, "I need someone official to be with me." As we started to make our way towards the elevator, I notified the nurse, and she entered in a code next to the elevator to disengage the alarm momentarily. When we made it downstairs, Joe, who was in charge of fixing the treadmills and other gym equipment, was already busy fixing someone else's wheelchair stabiliser bar. Joe told us that he had to be with another resident, but that he would come up to see Ryan after lunch.

In the following week, Ryan was still not happy with his foot pedals. At lunch, other residents began to ask me, "So how's Ryan?" When Ryan started making his way into the dining room, several of the residents raised their hands in an effort to get my attention. They began to see me as Ryan's 'personal caregiver'. After lunch, and after Ryan was taken to his toilet by the caregiver, Francis said to me in the hallway, "Ryan doesn't get around much. Does he even listen to the radio or watch TV?" I had the feeling that Francis was fishing for some answer or indication of Ryan's condition. I knew he had slight dementia, but I was still unsure of his feet, and why he had been in the health and rehabilitation centre for so long.

Ryan began complaining more about his foot. He expressed a concern that his condition would not allow him to be 'good at socialising with others'. He thought that therapy could be a good idea, and I asked him if meant physical or mental. To this, he did not respond. I asked him if he wanted to get more therapy, and he said yes. We both agreed to take a small trip to the therapy department. We made a stop in the gym and watched people on treadmills. All the therapists were busy with their residents, and so I initiated a small game of catch and throw with Ryan using a sponge-like ball. One of the therapists noticed us and directed us to see Erin in the main therapy office. Erin was a bit surprised to see us, because we did not have an appointment. I told Erin that Ryan wanted to seek out some therapy sessions for his legs and feet. Erin looked at us and said, "Well, since Ryan is on Medicaid, he doesn't qualify for PT treatments unless he pays extra. If he had an injury and had to be hospitalised for more than three days, then that would be covered." We left the office, and Ryan said, "I think I feel better. I'm still glad we came down."

For Ryan, his feet were certainly part of the problem. Because he couldn't walk or stand, and he was too heavy for his wife to assist with his transfers, Ryan had to move out of his house. In addition to his post-polio and the dementia brought on by the stroke, he was condemned to limbo at the health and rehabilitation centre. Ryan was growing more disappointed and frustrated. He wanted to be with his wife at home and help her with the housework. Although she is not in a wheelchair and can still move about, Ryan felt guilty and told me that he wanted to, "Work on getting better, so the building will let me leave." When I discussed things with Deena, the social worker, she said that they have already tried having him move back home. She said, "The structure of the house and the narrow doors and passage ways won't allow Ryan to move about easily in his wheelchair. We tried another option, but there are financial loopholes as well, so he'll be staying on the second floor of the health and rehabilitation centre." She told me that before I came to Tacoma Pastures, people had already been working with Ryan on his foot obsession. Deena informed me that, "Ryan gets caught up in these unhealthy associations, and as a result gets depressed. We had him working with a psychologist when he started revisiting the whole foot ordeal. He is working with a psychologist now." Since my time with Ryan, I only witnessed one occasion when a social worker with a brown cardboard clipboard asked him a few questions one afternoon. Even

though Ryan was fully aware that his feet and lower legs were preventing him from leaving Tacoma Pastures, the nurses and the social workers wanted him to focus on something else. His frustration and the fact that his condition was both a physical and an emotional barrier became relatively clear over time. Scheper-Hughes and Lock state that the, “ethnoanatomical perceptions, including body image, offer a rich source of data both on the social and cultural meanings of being human and on the various threats to health, well-being, and social integration that humans are believed to experience”(Scheper-Hughes and Lock 1987, 18). Ryan’s feet and legs became a point of alienation, and something that he had to work on. He expected to be healthy, strong, and fit. Ryan wanted a corrected body, not so much because of any need to fit some normative prescription for ‘successful ageing’, but because he wanted to avoid being in his words, ‘useless’. He wanted to avoid what Scheper-Hughes and Lock identified as a particular cultural articulation of laziness. Commenting on the work of Beatrix Cobb, Scheper-Hughes and Lock state that, “Among rural Midwesterners laziness is a most serious moral failing, and “spinelessness” is as reviled as godlessness. It is little wonder that a therapy concerned with adjusting perceived malalignments of the spine—chiropractic medicine—would have its origins in middle America”(Scheper-Hughes and Lock 1987, 18).

Two months later, I made my way towards the second floor, and spotted Ryan there in front of the elevators. I knew he wasn’t going anywhere; Ryan had an alarm attached to his wheelchair, and anytime he tried to get on the elevator or even near it, he would set off an alarm. I had been spending quite a lot of time with Ryan, helping him track down things and assisting him with various mini-excursions, like finding new TV remote batteries, and trying to get his foot pedals readjusted again. I suspected he’s probably sick of me, and is guilty or getting very nervous that he is, and in his own words, “Taking up so much of my time.” Ryan exclaimed, “Don’t worry about me today; I don’t have anyone to show you.” I didn’t leave, but I did take a step back and asked him if he was alright, and if he needed anything.

He thought about it for a good few seconds and came up with, “Well, yes, I need a new shirt.” I wheeled him back to his room, found a nice shirt and a brand new red sweater he had never worn. After the caregiver changed him, he turned to me in his room and asked, “Who do you know?” I asked him, “Why? What do you mean?” He said, “I need to

know if you are working for someone.” “Well, Ryan, you know I am just a volunteer and an academic researcher. I don’t work for anyone per se. I am doing this for myself.” He said, “You could be a secret agent, collecting info for someone. It’s just strange that you are here. Don’t you have a job or a family?” I said to him, “Look, I am not a secret agent.” He responded very appropriately, “Well if you were, that’s just the kind of thing you would say.” “Come on Ryan, you have to use your reasoning to determine whether or not I am a secret agent. Haven’t I always respected your space, and not asked you really personal questions?” Ryan nodded and said, “Well, yes, you’re right. I just need to know who the friends and foes are I guess.” He then said, “I know just the thing. You’ve got too much free time. You need more problems to work on. Me and Pat will think of a task for you next time you come by.”

Ryan also assigned himself tasks. For example, he had an old semi-functioning typewriter, and wanted me to help him edit a letter to one of his brothers. I offered to help him set up the typewriter, but he wanted to do it himself. Eventually, it took him (with the help of his son I assume) a month to finally get the typewriter set up. One day, Ryan had missed a movie showing, and was very upset that he was not informed. He was under the impression that it was cancelled, and decided to write a letter to the staff. He wanted me to edit it. The letter was never written, but it gave Ryan the opportunity to say that he was working on *something*.

* * *

Out of all the volunteers, only two of them had been at Tacoma Pastures for more than a year. Most of the volunteers worked at Tacoma Pastures for only a short amount of time. Some of the volunteers were students, others needed to give forty hours of time in order to fulfil court-ordered community service sentences. Because of this, volunteers did not build any lasting or significant relations with the residents. The volunteers were able to visit residents, and many of them had lengthy and personal conversations, but for the most part, the volunteers acted as assistants to the recreation staff members. They helped set up activities and stuck around for clean up. Many of the residents were friendly and welcoming; they appreciated the volunteers by thanking and praising them, especially when the volunteers were calling bingo. As a volunteer, and someone

who was hanging around rather regularly at Tacoma Pastures, the residents grew accustomed to me. At first, I felt uneasy about wheeling residents around. When I asked them whether or not they wanted me to push them from their rooms to a location down the hall, most of the residents declined. At first, they were courteous and definitely wanted to appear 'able-bodied' in front of me. As time went on, however, many of the residents felt comfortable letting me know that they were tired and even lazy. One woman, who was adamant about doing everything herself including changing the announcements on the bulletin board half-standing up from her wheelchair, eventually let me wheel her around on the days she felt lethargic. Because the staff got used to me as well, I was able to lobby them on behalf of my residents. I knew that the nurse's station kept two packs of cigarettes and a small bottle of blended whiskey for Ryan. His wife did not approve of his smoking, but even the staff recognised that it was Ryan's 'right' to have a smoke. After all, according to one nurse, "What's the worst that can happen to him?" I took Ryan outside for the occasional smoke, and also refilled coffee for residents who were not technically supposed to have a second cup. I did not refill their cups that often, but on some occasions when my residents pleaded for another cup, I caved in, diluting the coffee with hot water. Other times, I gave them decaf. Although I began wheeling my residents to and fro, I caught myself letting them pick things up they had fallen on the floor. I recalled a presentation I attended, that reinforced the idea that the elderly need to be mentally and physically engaged, and that it is always better for the elderly to continue doing things, rather than to succumb to atrophy in the evil garden of sloth. As a volunteer, I had time to let the residents reach down and fumble from their wheelchairs for a dropped pencil, or a wayward Styrofoam cup. It was good for them and part of the physical therapy, I told myself.

In the health and rehabilitation centre, the residents were hoping to get better; they wanted to be somewhere else. Francis, a woman resident, whose room was next to the nurse's station kept pictures and brochures of a brand new assisted living complex on the west side of town. It was here, that she wanted to move to. In between activities and one-on-one visits, I often spent my time in the empty dining room of the health and rehabilitation centre, waiting for someone to wake up from a nap or to get ready to put together the day's final activity before dinner. On many of these occasions I thought to myself: "The residents are vulnerable; their personalities and quirks are harder to mask

in old age, especially when they also have to contend with a debilitating disease. They are out there, like a book, opened to a page, which was not of their turning.” I thought that there were several gazes going on at Tacoma Pastures. I told myself that the nurses and the caregivers saw the residents through a narrow microscope, and that the recreation department and their volunteers, however, viewed the residents with much sympathy and pity. This reactionary view would change over time, especially after I started working as a part-time caregiver. My time as a volunteer came to an end when I was asked to interview for a part-time position as an uncertified caregiver. Things would change for me, but this did not occur overnight.

Chapter 3: Memory Care: Tales from the 3rd floor

Caregivers wear multiple hats. By describing how care unfolds on the third floor of Tacoma Pastures, this chapter explores the different tasks caregivers perform in their daily interactions with residents who are diagnosed with some form of dementia. Caregivers have a checklist of certain tasks to perform every shift, and what lies outside these routinized tasks also constitutes much of their hidden and meaningful work. Caregivers are sometimes friends, communicators, observers, adjudicators, and audience members. For instance, I witnessed an elaborate interaction involving one caregiver who had to attend to a resident in his final week of life. A communications professor decided to go on hospice, refusing any food or drink. This extremely tall man who prided himself on growing up in the Upper Peninsula of Michigan, and who eventually became an advertising guru of sorts decided that his time was up, and he was going to direct his final commercial. Rather than feel any pity for him or his family, a young female caregiver decided to sit with him at his bedside, and eschew what was outlined in his care plan. Instead of forcing him to take any food or water, she made jokes and attended to him as a stewardess might in a first class cabin to a passenger who was already full with food and wine.

Caregiving for the elderly, especially for those persons suffering from dementia requires patience and creativity. Redirecting residents living in a unit that has been locked to prevent them from wandering and getting lost takes on a particular form of care and surveillance. Creative lying is a common strategy employed by many caregivers who work with dementia residents. It is used often, and without much hesitation. Caregivers are confronted with an array of creative lying techniques; they say that what matters is not necessarily the 'truth', but entering the reality of someone with dementia and Alzheimer's. In this way, caregivers have to create new modalities of empathy based on inaccurate understandings and memories. This kind of interaction is performative and sheds light on conventional ideas of interaction ritual. Being able to communicate with someone who is living in a very 'different today' takes an amount of imaginative resources in the name of 'getting things done practically.' For many of the caregivers at Tacoma Pastures, this was not so much an issue of empathy, but rather one of radical

translation.¹⁹ What follows is an examination of what happens when caregivers work with older persons diagnosed with dementia.

* * *

In a review of Steven Rose's *The 21st-Century Brain: Explaining, Mending and Manipulating the Mind*, Ian Hacking writes that, "One aspect of the futurology of brain science is now of special interest to baby-boomers and older people [...] If we do not die, soon enough we will become increasingly senile. Many of us will develop dementia or its more specific form, Alzheimer's disease. That name seems to scare people nowadays more than cancer does" (Hacking 2005). Even though the residents at Tacoma Pastures are not worrying about the science of the brain, or the philosophical debate about the nature of the mind and consciousness, caregivers are trained to deal with dementia from a particular idea of brainhood (Vidal 2009). For Hacking, he is sympathetic to the idea that the, "[human] brain has to become part of a social person" (Hacking 2005), and that Alzheimer's for all its neurological curiosities and unknowns is very much tied to the history of late 20th-century medicine and the success of lobbying and advocacy groups. Many in the medical profession consider Alzheimer's a disease (of the brain) and not a set of symptoms and disabilities linked to issues of personhood and the changing nature of social relations. Hacking asserts that, "[...] perhaps we should reclassify it not as a disease but as a handicap or disability, which would substantially change its status and administration within the social net" (Hacking 2005). To complicate matters even more, Alzheimer's is only conclusively diagnosed via autopsy. In the meantime, caregivers attend training sessions that locate dementia and Alzheimer's within the brain. Even though I started working as a caregiver in Memory

¹⁹ Although W. V. Quine's radical translation is a project about the theory of language, meaning and reference, I am speaking here of a practice of radical translation which is at once inter/intrapersonal and intertemporal. Caregivers do not operate with an invariant conception of communication (Quine 1960). When spoken language fails so many of the residents in Memory Care, and given the fact that there is no universal dementia-manual for translating the thoughts/emotions of one person to another (even in and through language), the condition of suspending prior linguistic knowledge approximates a certain reality for the residents. A theory of radical translation is thus a useful concept for thinking about the heuristics that obtain between a caregiver and care receiver. In a sense, this practice gestures towards Donald Davidson's understanding of radical interpretation (Donaldson 1971).

Care without any formal training, I attended a few workshops at Tacoma Pastures on how to work with residents with dementia.

These workshop classes touched on areas such as dealing with challenging behaviours, improving caregiver interactions and enhancing communication skills with residents, as well as with learning about dementia and its effects on the brain. Because memory loss is not the only symptom associated with dementia, caregivers were instructed how to work with residents who suffered from depression, hallucinations, drowsiness, inactivity, and a host of other psychiatric symptoms. Residents with dementia also have trouble speaking and finding the right words, and can require assistance with basic mobility. In one of the training courses I took, Jennifer, a middle-aged woman instructor, began the class with a picture of the healthy brain and then launched into a description of how Alzheimer's affects the brain by way of atrophy, neuritic plaques, and neurofibrillary tangles. We also learned about the mini-mental state examination (MMSE), a 30-point short questionnaire used by the resident doctor of Tacoma Pastures to quantify cognitive function and screen for cognitive loss. Jennifer moved beyond the medicalized brain to discuss how caregivers should interact with the residents. She told us that we should always make eye contact and speak slowly. Jennifer said, "It is important to explain things over again, and to engage in positive reinforcement. Try avoiding getting them stressed. This means avoid situations that will cause the resident agitation and added confusion. One simple way to do this is to remember: don't turn your back to the resident when picking out their clothes." The instructor continued with other examples. We were told that when confronting certain residents with food choices, it was better to ask yes or no questions. Instead of asking them whether or not they wanted chicken or beef, for example, Jennifer said that we should always phrase the question as: would you like chicken/beef, yes or no? With respect to creative lying, we were told that if someone had progressed dementia we should avoid reminding them about their deceased spouses. She said, "Don't lie exactly, but rather than confirm whether or not their spouse is still living, validate their feelings. This will help you with your caregiving. We can't change what they think, but we can change how they feel." When residents resist care or are uncooperative, Jennifer said to re-approach them at a later time. She said specifically, "Give them ten minutes or so, and if they are taking meds, wait until after they have taken their pills to re-approach." She concluded one

class by telling us that dementia is a condition of the brain, and that we must re-orientate ourselves to this fact. Jennifer said, “Remember, talking is in a different part of the brain than singing. Think about how this would apply and help you with your techniques for getting a resident’s attention. Because so much of what you do can help the residents feel better, you must let the residents feel comfortable. This requires you to help them preserve a sense of familiarity. Dementia has no memory of routine, but for them it will feel right.”

* * *

Even though there are residents with mild dementia living on the other floors of Tacoma Pastures, Memory Care is a segregated floor devoted solely to residents with dementia. The residents in Memory Care have been clinically diagnosed with medium-severe staged dementia, and require Level A Memory Care Services. Those who are bedridden and have very limited mobility require Level B Memory Care Services (see figure 3). For the other residents who suffer from dementia on the other floors, they do not automatically move to the third floor, because either their dementia is still relatively mild or there is simply no vacancy on the third floor.²⁰ In his study of a nursing home in Denmark, Jens Kofod points out that the context of dementia residents in nursing home settings is very different than what one might imagine in a mental hospital. Regarding dementia, Kofod goes on to say, “These residents were mostly unable to negotiate a position in a relation to staff, as they were mainly unable to identify who they were and often also where they were” (Kofod 2008). For the Memory Care residents and caregivers at Tacoma Pastures, this was not always the case. But before going further, a few words about the physical layout of the third floor is in order.

²⁰ During my time at Tacoma Pastures, there was not one vacant room on the third floor.

Figure 3 Memory Care service/care levels

MEMORY CARE SERVICES

Level A

Care Level A includes any or all of the following services:

- Laundering of flat linens weekly
- Additional light housekeeping (bed made, clothes hanging)
- Night checks
- Assistance with scheduling appointments
- Verbal reminders for all activities of daily living
- Bathing assistance twice per week
- Routine assistance with continence programs
- Screening for therapy (occupational, speech, physical)
- Personal assistance with daily grooming needs
- Extensive medication management and administration
- Assistance with escorting and transfers

Level B

Care Level B includes Level A, plus any of these additional services:

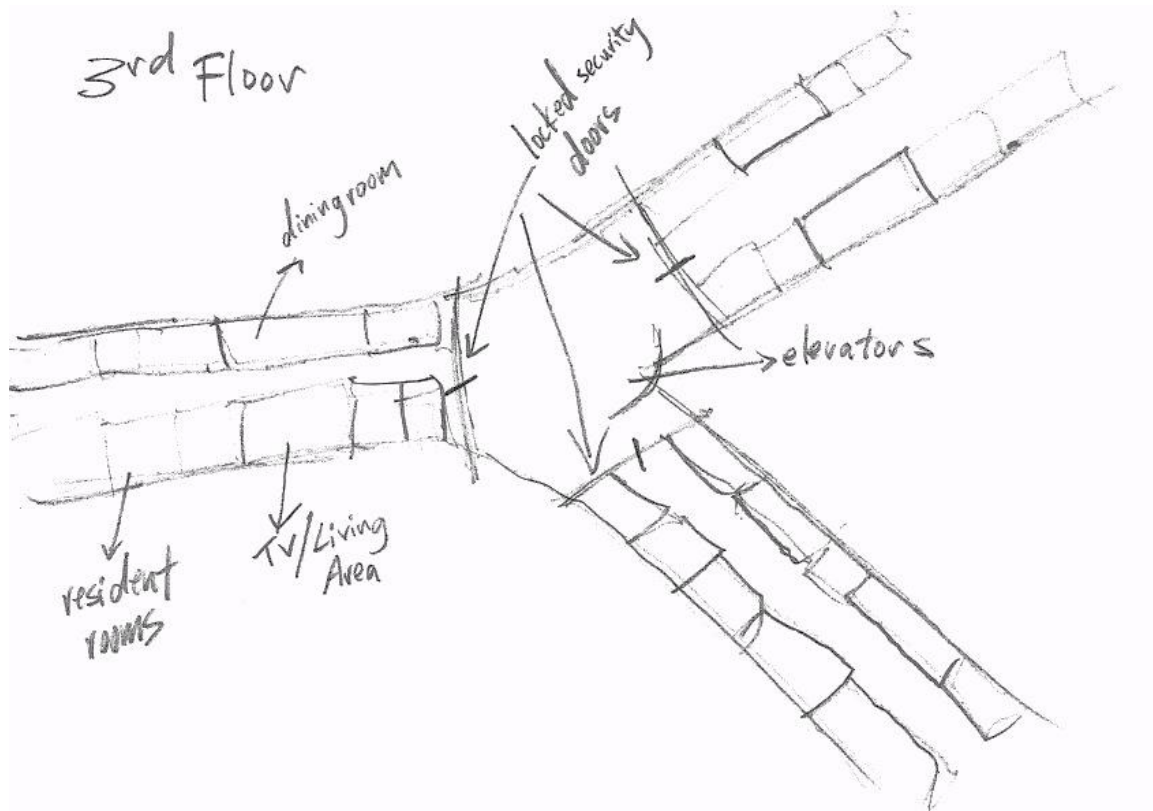
- Bathing assistance twice per week by 2 caregivers
- Personal dressing assistance with zippers, buttons, socks, shoes, belts, etc. provided by 2 caregivers
- Personal assistance with clothing selection and dressing needs provided by 2 caregivers
- Personal assistance with daily grooming needs provided by 2 caregivers
- Extensive medication management and administration provided by 2 caregivers
- Assistance with escorting and transfers by 2 caregivers

The 3rd Floor Layout

Many CCRCs, including Tacoma Pastures, are designed to have a section or floor committed solely to dementia residents. At Tacoma Pastures, the Memory Care on the third floor offered what the management called ‘dedicated cognitive support.’ The director of the resident centre (which includes Memory Care) told me a few weeks after I started working as a caregiver that, “Memory Care is a place where everyone feels safe. We work hard to help them continue living, and to make sure that they have the support they need. We do this by bringing our services like physical therapy to them, so that they can maintain their dignity and sense of self.”

On the third floor of the main building there are three wings that constitute three separate neighbourhoods. These neighbourhoods, which are named after three local rivers, make up what is known officially in Tacoma Pastures as Memory Care. Because the residents on the third floor suffer from Alzheimer’s and other dementia-related symptoms such as Huntington’s, Parkinson’s, Diffuse Lewy Body, and Creutzfeldt-Jakob Disease, each of these three wings are electronically locked. Additionally, taking the elevator from the third floor requires entering a four-digit code. The caregivers who work in Memory Care are usually assigned to just one of the neighbourhoods: Little Red, Placid, or Clearview. Each neighbourhood has about twenty residents, ten residents on each side of the hall. When I was working as a caregiver, a married couple occupied one of the rooms. The husband had dementia, but the wife did not. After a month, the wife moved downstairs to be on her own. The Little Red, Placid and Clearview neighbourhoods have their own living rooms, which feature a fairly large television, and a dining room, but no kitchen (see figure 4). The hospitality staff delivered hot meals up from the ground floor using a trolley. Additionally, only one med tech was assigned to the entire third floor, and each neighbourhood was assigned two working caregivers.

Figure 4 Sketch of a 3rd floor neighbourhood



The layouts in all three neighbourhoods are fairly identical. The hallways are brightly lit, and the residents' rooms, while smaller than the ones on the other floors, have newer carpet. Additionally, the bathrooms have all been newly refurbished, with standard issued plastic shower curtains. The smell of urine and used wet towels often persists in the residents' rooms. Some of the caregivers brought fragrance sprays from home that they would use during their shifts. In the Placid neighbourhood, two of the caregivers decided to purchase a plug-in wall air freshener for the hallway.

In the Clearview neighbourhood, to take just one example, the dining room is located right across the living area. The dining room has a total of four tables, a medium-sized refrigerator and a sink. There are no stoves or ovens. As soon as the hospitality staff is done serving and finished cleaning up, they lock the dining room. This is done to prevent residents from going in, and getting into the refrigerator for 'unnecessary snacks.' The living room area directly across the dining room has two sofas, a love seat, and multiple chairs (see figure 5). There are some small tables next to the sofas, and a table that once belonged to the dining room. The caregivers filled in their care plans and

rested in between their tasks at this table (see figure 6). Because the living area is carved out in the middle of the wing, caregivers would often sit in one of the chairs next to the sofa, enabling them to keep an eye on both ends of the corridor and on any residents trying to tamper with the security pad next to the exit doors.

Figure 5 Sketch of the 3rd floor common living room area



Figure 6 Care plans and Point-of-Care laptop station



Each neighbourhood is electronically locked. Residents looking to leave Memory Care for a medical appointment, or even to the beauty salon just downstairs need a caregiver escort. For many of the residents with severe dementia this is a safety requirement. Most of the residents in Memory Care were labelled wander risks in their care plans. Every now and then, a resident managed to escape Tacoma Pastures. This happened when a resident was left unattended after the conclusion of an activity or some kind of social function downstairs. Sometimes, the caregivers lost track of the residents, especially when they were in the midst of taking residents back to their respective rooms and neighbourhoods. In the neighbourhoods, and when the residents are not in their rooms lying down or being taken to the toilet, some of them sit in the living room. The residents who are in the living room, however, do not usually pay attention to the television. Unlike the nursing home stereotype, where residents are portrayed as falling asleep in their chairs with their heads propped up with the palm of their hand, the residents in Memory Care did not appear bored nor did one get the impression that they were waiting eagerly for a family visitor to come by. They sat and exchanged short words and one-liners with each other. Some of these exchanges amounted to nothing but a confirmation of some situation or simple commentary. For instance, when Christine who is able to navigate back to her room using her walker, gets up out of the

sofa, others will simply give her a quick look. Sometimes, a resident will remark, "I am hungry." When Christine walks past the residents and in front of a caregiver, the caregiver greets her with a simple "There you go, go on Christine." One of the other residents nearby will simply utter, "Yup." Residents also pace back and forth between their rooms and the living area, and this routine can take up most of the time in between meals. Some of the more anxious ones will find reasons for wanting to leave. Reynolds was one of these residents, and would get very anxious after lunch. He would dart towards the door and lean against his walker, blocking people from coming in and leaving. On such occasions, the caregivers would have to find ways to divert him back to the living room area. The caregivers often complained that the recreation department was not doing their job and providing enough things for the residents to do. In the case of Reynolds, the caregivers found a strategy that seemed to keep him away from the door. They would put in a CD of old folk songs in the music player next to the television. When they did this, Reynolds would sit down and sing to each and every song, for at least the duration of the CD. He did this nearly everyday. Residents, who were lucky enough to be assigned a volunteer or had a nearby family member come visit, would be taken for walks around the campus. On wintry days, none of the residents wanted to go outside even for a breath of fresh air just under the main entrance canopy.

In Memory Care, everyone's door was kept open throughout the day. Even at night when people were sleeping, the majority of the doors were left cracked open. Some of the residents wanted them cracked open, so as to know what was going on. For some of the other residents, especially the ones that had an unsteady gait or suffered from Parkinson's, the caregivers needed to keep a constant eye on them. They did not want them to fall, or walk to the toilet by themselves. Even when the caregivers were giving residents their showers, they left the doors slightly open so they could be alert to some of the other things going around. Because of this, incidents and various episodes frequently occurred out in the open.

Susan

Susan's room was next to the common area. She had a couch facing the window, and a large television, which she never turned on. The room itself was rather plain with no framed pictures or any photos of her family members. When I first started working on the third floor, the fulltime caregivers told me that all I had to do was knock on her door around 7:45 a.m., to remind her that it was time to get up and get ready for breakfast. My first encounter with Susan, however, occurred when I was working as a volunteer. During that time, I escorted her with her walker to various events and social functions on the main floor. Susan was just over seventy years old. She was always very courteous and thanked me multiple times each time I helped her. On Sundays, she slept in past breakfast. She was always ready for someone to take her downstairs to view the local mass, which was shown on the large projection screen downstairs. Every other Thursday, the priest from the local Catholic church would come and conduct mass in person at 11:00 a.m. Susan always sat near the front, no matter what the occasion. During holiday parties, she would always welcome me to sit next to her. She did not need the company, but always enjoyed someone to interact with. When I was a volunteer, I sat with her for short periods of time and ate snacks with her. I also offered her a never-ending cup of black coffee. She would grab my arm firmly, gripping my forearm saying, "You are strong and young." During one of the Christmas parties, I sat with her halfway through the event. Being a volunteer and quite naïve at the time, I did not realise until much later that she had a bowel movement. I did not want to interrupt her fun, and as far as I could tell, no one else really noticed. Therefore I sat with her the rest of the evening, and as soon as the event concluded, I rushed her to her room afterwards, alerting the floor's caregiver that she needed to be changed. As I took her up to her room, she thanked me and said that she was glad I did not leave her.

After a month of working on the third floor, I began to notice that Susan was not getting up by herself. She would often miss breakfast. The fulltime caregivers also took notice of this, and instead of allotting more time to help her up and dressed, they started to forget about her until just before lunch. Because she did not take any medications in the

morning, the med tech and the caregivers were not too fussed about this. Things, however, began to change when she started coming into the hallway half-dressed and without her wig on. The caregivers could not let this happen, and so the fulltime caregiver working in Susan's section and the med tech decided that she should be up and dressed like everyone else for breakfast.

Susan required a lot of coaxing, but she usually got up on her own. I started coming into her room earlier in the day, knocking first, and then opening up her door with the master key, which was attached to my electronic pager. On a typical day, I would enter and open the blinds notifying her that it was time to get up, and that I would come back in ten minutes to help her pick out her clothes. Susan enjoyed it when I prepared her outfits. She would always say to me, "You are great! You are the best!" I would pick out something for her and she would say, "Great!"

Susan began asking incessantly and literally every five minutes, "Have you seen my son?" She had a daughter and a son who lived within ten miles of Tacoma Pastures, but it was her son, the fireman, that she was always talking about and looking for. When she was in the bathroom brushing her teeth, I made her bed, and got her clothes ready. She would often pop out of the bathroom, half-naked, asking for her son. It did not matter whether or not he was coming to visit later on; she would ask for him repeatedly. I witnessed other caregivers replying to her, "Yes, he's coming. Just sit down and eat and he'll be right there." This was the usual strategy that caregivers working with dementia residents were taught. Diversions and necessary lies were a tactic many caregivers had to employ on a minute-to-minute basis. I found myself, lying sometimes, and at other times trying to change the subject. I could not decipher whether or not having the certainty of knowing that her son was coming to visit would make her happier, but what I did realise was that this routine of hers never ceased. When her son did come to visit, he would take her by the arm, and she proudly reintroduced him to everyone as her son, the fireman.

Susan became gradually more disoriented, and would often only put on half of her outfit. Additionally, she would wear her wig without the inner support that would fit nicely around her head, and this made her hair look as if it was teetering off. At first, I felt that she would be self-conscious without the wig, and wanted me to see her only

with her wig on. But as time passed, she allowed me to help in the bathroom with adjusting her wig. She remarked that, "I am ugly, but you, you are great!" I said to her, "Nonsense," and began not only helping her with her inner support and wig, but I even found a way to brush and style her wig which she liked very much. As a finishing touch, I reminded her to take her walker with her to the dining room, and cleaned her glasses so that she could, at least to my mind and desire, approach the day with clarity.

Anita

Anita was the mother of a high school superintendent. She was born in Latvia and came to the United States in her early twenties. She had made a name of herself, becoming one of the founding members of a local potter's guild. Her room was in the Little Red neighbourhood of Memory Care, and towards the farther end of the corridor. She had a small bed pushed up against the wall, and a clumsy steel bed rail that was always crooked. There were a few Latvian poetry books on her desk, and a cabinet with four very distinct yet unimpressive mushroom clay figurines. Anita also had a fairly large lightweight steel rollator walker that barely fit through the door. Because of this, there were scratches pockmarked all over the lower part of her doorframe. I did not work regularly in her section, but I was in her section at least once a week. Before I started, the fulltime caregiver in the afternoon shift, who I had to consult with during the changeover, notified me that she needed as much encouragement as possible and, "If she gets aggressive, do not force the issue, but re-engage later." Anita suffered from Parkinson's Disease Dementia and required extra assistance, because she was unsteady on her two feet, and was likely to fall at anytime. Even though she was very strong and in her early eighties, her gait was extremely unsteady. Additionally, Anita's care plan stated that she did not want a male caregiver to help her with toileting, dressing and showering. Because of this, I had to swap residents with someone else whenever I was in her section. On several of these occasions, the caregiver working with me became annoyed that I had to swap with them. They did not want to work with Anita, because according to them, "She always resists care." She would not get up from bed, and would often lie past lunchtime. To add to the pressure, her daughter who the caregivers said did not have a good relationship with her mother wanted her up and dressed before breakfast. The nurses even began noticing Anita's resistance and asked all the

caregivers to try their best to go into her room to help her get up. Since she needed physical help getting up in the morning, and because I was a male caregiver, she would not budge, especially for me. Anita pushed away many of the caregivers and as a result, many of them did not want to engage with her. Many of the caregivers voiced their reluctance to work with Anita. One of the caregivers even said to the nurse one time when referring to Anita's room, "I love my section, except for that black hole over there." Jules Henry once remarked in his cultural analysis of human obsolescence in the nursing home that, "It will have been observed that the law of distortion and withdrawal does not state what becomes of the distorted person, but simply that others withdraw from him. I have pointed out, however, that the withdrawal of others increases his anxiety and disorientation and thus further increases withdrawal" (Henry 1963, 436).

Getting the other caregivers to help me with Anita meant pulling them aside from their workflow, and this made things more stressful and tense. Nevertheless, I helped to make up for the annoyance by offering to swap for a resident who required the same amount of time. This usually meant that I picked up someone who I had to help shower, which also entailed a full change of bed linen and towels. As time went by, Anita's condition became worse. Not only did she refuse to get out of bed and dressed, but she began speaking only in Latvian. One day shortly after lunch, she refused to let anyone in her room. She was walking around in her room, without her walker, in a nightgown and adult briefs. One the caregivers who I was working with became frustrated. I suggested that she call the head nurse. When the nurse came, Anita had barricaded her room with two chairs. The nurse spoke to her and said, "Anita, you have to take your shower, it's been a week, and we are here to help." Anita began mumbling something in Latvian, and when the nurse reached over the barricade, Anita muscled up the strength to pick up a light chair and thrust its legs towards us. She then moved the chairs and barricaded the area in the hallway, blocking not only access to her room but also three other rooms. The nurse said that my presence, as a male caregiver, probably added to her anger, and so I was assigned to the fourth floor for the rest of the day.

I was not assigned to Anita's section for another month, and when I eventually returned to work in her section, I learned that her daughter was furious that a male caregiver was still assigned to her room, even though I did not touch her or even help her with getting

up and toileting. When I returned, however, Anita was very sedated. The resident physician at Tacoma Pastures, who was also Anita's personal doctor, decided to increase her medication. Jane, another caregiver who really liked Anita, told me that this was Tacoma Pastures's way of dealing with problems. As a result, no male caregiver was assigned to her section again, and when I did work in Little Red, my section comprised of the other side of the corridor.

Anita's condition soon worsened. She became very weak, and appeared dry in the mouth and dehydrated all the time. Whenever she was in the dining room, she did not eat, and even when the caregivers would feed her soup, the soup would just spill out of her mouth and onto her bib. Eventually, Anita became bedridden. I never saw her daughter once, although I knew from the med tech and other caregivers that she had come to Tacoma Pastures to visit with the head nurse on the fourth floor and with the resident centre director. Jane told me after Anita passed away that, "The meds really did her in. It's a shame. But what can you do?" Jane fed Anita water through a syringe that Jane had purchased herself from a local pharmacy store. Anita grew more faint and died in bed one late morning.

Eve and Kent

Eve was born in Germany, and came to the United States to practice medicine. Before she moved to Tacoma Pastures, she was famous for being one of the first woman optometrists in the area. In addition to her medical career, Eve was also an amateur violin player. She never married, but kept a close circle of friends who often provided her with much support. She was getting too old to drive and felt that she needed to give up her participation in the community orchestra. Her friends, however, insisted that she should continue. During her last year in the community orchestra, her friends often drove her to rehearsals, especially on those wintry nights where the country roads iced over. As a caregiver in her section, I came to Eve's room at around 6:45 a.m. After I had passed out cups of water to everyone in the section, I entered her room and turned on the bathroom light. I turned on the sink, and took down a small washcloth to get it warm and wet. After wringing the washcloth, I operated Eve's mechanical bed and raised the upper part. She had lost much of her ability to speak due to a stroke, but she

could still communicate with me in small phrases. I spoke German to her, which she enjoyed and responded enthusiastically to. After I issued her an energetic “guten Morgen,” she would angle her head away from her neck so that I could wipe the sleep out of her eyes. Pressing on the other button in the bed control enabled me to get Eve into more of a sitting position. Once she was in this position, I brought the wheelchair over, put on the brakes, and lifted her from the bed and on to the wheelchair. Once we were in the bathroom, I told Eve to grab the safety rail next to the toilet roll. She lifted herself up out of the wheelchair for a good ten seconds, which gave me enough time to lower her adult briefs, and to swivel her onto the toilet. When she was on the toilet, and with the sink still running, I handed her a toothbrush with paste. I took the same washcloth I had used on her face, and rewet it in the sink. With this washcloth, I wiped her legs and applied lotion, whilst wearing the mandatory latex gloves. Once she was finished brushing, I gave her a small cup of water and a plastic hospital-like pan to spit into. At this point, Eve looked at me and said “Ow...ouch.” She always did this whenever she knew that I had to do something that would make her knees bend. Even when operating the bed to get her to sit up straight, she would pronounce the anticipatory ‘ouch.’

After brushing her teeth and while still sitting on the toilet, I would gently take off her nightgown and hang it on the bathroom door. I applied some lotion on her back, stomach and on her arms. Somewhere during these activities, I would also flush the toilet for her. A pair of ted hoes (compression stockings), which I had to put on her feet, were always ready to be found hanging on the shower curtain rod. Ted hoes looked like tight leg stockings, but they had two holes that only a few toes could peek through. These ted hoes helped to relieve her heavy and achy legs via compression therapy. They were hard to put on, and required Eve to endure a few seconds of mild discomfort. After I got these ted hoes on, I helped put on Eve’s bra, which sometimes also elicited an ‘ouch,’ but a much softer and less sincere one. Once I put on her t-shirt and one of her favourite sweatshirts, I then slipped through her feet a new pair of disposable briefs, and a pair of baggy cotton pants. I also put on her untied sneakers. Finally, and only after making sure that she was indeed finished with using the toilet, I brought the wheelchair closer to the toilet and asked her to grab the handrail again. She did this every time successfully, without ever slipping. As soon as she was up and hunched over

the handrail, I took some cleansing wipes from a package and wiped her bottom and front. Immediately following this, I pulled up her briefs and pants, and made sure her shirt was straight, and eased her back into the wheelchair. Then, I wheeled her out of the bathroom, shut off the lights, and looked for her watch and glasses. I slid on her wristwatch, but let her put on her glasses. Only then, did I comb her hair and tie her shoes. Her foot pedals were never far away, and I put these on and wheeled her to the dining room, leaving her in the hands of the hospitality staff for breakfast, while I assisted the nine other residents.

Eve did not have any family relatives in the US, but she did have someone who treated her like her own mother. Patsy, whose own mother was in another Memory Care neighbourhood down the hall, used to live in the house next door to Eve before she moved to Tacoma Pastures. Patsy knew that she had no family relatives to look after her. Because of this, Patsy started looking after Eve and was granted power of attorney for her. I learned from Patsy that Eve was estranged from her family in Germany, but Patsy did not know any of the details. Sometime had passed, and it was in late winter when Eve began going to the hospital more regularly. She had developed a cough and was not eating very much. One resident who did seem to miss her was Kent. This resident lived across the hall from Eve. Kent, who was over ninety years old, grew up in a rugged area of the country. His father was a copper miner. Before his retirement, Kent was a well-known professor of communications, specialising in broadcasting. He had three children, two sons who were also academics and a daughter who never married and never held a fulltime job. Kent took a liking to Eve, and would always help her in the dining room. Even though Eve never said anything to him directly, Kent would give her his dessert and would often leave his walker to help her. This annoyed the caregivers, because they were afraid he would fall. The caregivers working in Kent's section thought he was mean and aggressive. They learned that trying to get him out of bed would usher in a scolding. Kent was not shy and would often yell at the caregivers, especially male caregivers. In fact, Jacob one of the physical therapists had to quit trying to get Kent down to the gym, because Kent refused violently. On one occasion, I saw Kent lift his lightweight walker and use it as a weapon, trying to ward off Jacob from approaching any closer. After Eve passed away in the hospital, Kent decided that it was his time as well.

In the two weeks that followed, Kent refused to eat or drink anything. He was determined to end his life. On the second day of his fast, the nurse and the director had a meeting with his children. Following that meeting the nurse told us that there was nothing we could do. We couldn't force him to eat or drink. She also divulged to me that the two sons were not happy with the situation, and that things were complicated because of the return of his daughter, who was the black sheep of the family. The nurse said that the two sons saw her return as a way to get more inheritance. For the next few days, all we could do was offer water through a straw whenever Kent would take it, and to make sure that he was comfortable. Word of this soon reached many of the hospitality staff members and the caregivers working on the other floors. One of the female caregivers who told me that she really liked Kent said it was just awful how Tacoma Pastures was just going to let someone die. She came down from the fourth floor during lunch and said, "Why are we just sitting around, when someone is dying?" Another caregiver started to cry, and excused herself. Meanwhile a hospitality staff member and I turned to our residents and continued to feed them in silence.

The nurses brought a portable commode for Kent to make going to the bathroom easier. The family had hired a hospice counsellor to be with Kent, but Kent did not want him around. The counsellor handed me a business card and said to let him know if he could be of further assistance. His daughter started coming around and spent almost the entire day with him during his final week. Not once did I see his sons there. His daughter was the only one that he let feed him. Kent was coughing up lots of blood, and this blood was beginning to take the form of a very dark colour. Before his daughter could offer him slices of orange, which she had peeled, and which she would squeeze over his lips, I had to constantly wipe the blood from his mouth and sheets. The whole ordeal was rather painstaking and messy, and I had to change his sheets at least two times during my shift alone. After a week of this drawn out affair, he passed away sometime in the afternoon. Caregivers talked about Kent posthumously as a "Hard man, who always did things his own way." Another caregiver said that his only source of happiness was Eve, and that when Eve left he decided it was time as well.

Adorna and Brad

Adorna always kept her door slightly open, even while she was sleeping. When Adorna moved to Tacoma Pastures she lived on the first floor with her husband and then transferred to Memory Care after he passed away. Her room in the Placid neighbourhood of Memory Care was right next to the dining room. Every morning before I passed out fresh cups of water at around 5:45 a.m., Adorna was already awake. She often slept in the same clothes she wore during the day, and by the time I got to Adorna's room, she was already staring at me from her bed. We exchanged good mornings, and she would be up and about with her walker checking the weather. She knew that I had yet to change the bulletin board, which announced which month, date and day of the week we were in. After passing out cups of waters, Adorna opened up the small cabinet under the television and fetched the batch of cards that I had to choose from for the bulletin. I found the right day, and gave it to her to put into the empty bulletin slot. Adorna was under care plan level A; she did not require that much help with the activities of daily living. She could get up and dressed on her own. Because she was rather shaky in her gait, and appeared to be frequently twitching, I reminded her frequently to use her walker. On occasions when her twitches were rather bad, I would help her with her showers. She didn't mind male caregivers doing this, and enjoyed it when I scratched her back with the loofa. Out of all the residents in Memory Care, Adorna enjoyed her warm showers the most. Adorna could be forgetful, and I could see how she could struggle finding her way back to the room from the ballroom downstairs, but for the most part, Adorna was rather lucid. Adorna never complained about anything. She did, however, get very anxious. She would often ask me and the other caregivers, "Where should I be next? What should I be doing?" To this, and depending on the time of day, I would often say, "Well, you have another hour before breakfast, you can just relax. Perhaps you want to sit in the common room and watch some television." She would normally make her way to the sofa and glance at the television, only to get up and wander to her room and back, asking one of us again, "Where should I go? What should I be doing?" As I started to get to know her, she told me about why her Alaskan wolf sweatshirt was her favourite. She said that it was only her second marriage that saved her. She travelled and got to see the world with her second husband, and one of

the trips that she remembered fondly was a cruise to Alaska. She told me, "I come from a plain background. Meeting my second husband was the best thing that ever happened to me." She did not have a child with this husband, but had a son with her ex-husband. I saw him a few times, and he did not appear to have a job. In fact, during one of his visits, I overheard him saying to his girlfriend in the hallway that he was there to ask for a little bit of money.

As time went on, Adorna began to have trouble sleeping. Her distress was palpable. She would sit up all night in the common room shaking from the cold without any covers. Apparently this did not worry the third shift caregiver. When I came in on those early mornings and found her shivering, I walked her back to her bed. I was quite aware that I was actually tucking her into bed, and reassuring her that I would not forget her. I told her, "You have another hour of sleep. You didn't sleep at all and you need sleep." I turned off her room lights, and attempted to shut the door, but she used her walker to prop open the door slightly. I asked her if the light bothered her; she said she preferred it that way. On another occasion, Adorna was wrongly blamed for taking the clear waste bin bags that the caregivers stashed away in a drawer in the common room. When they disappeared, the caregivers said it was Adorna because she was the only one hanging about in the common living room late at night. Eventually, the caregivers found out that it was Erin, Adorna's neighbour, who was hiding away all the bags. Erin was under the impression that she was staying at a hotel, and since she could not find her luggage, she needed bags to pack up all of her stuff.

One day, a new resident named Brad moved into Adorna's section at the end of the hall. Brad and his wife moved to Tacoma Pastures together, but they were soon separated for reasons unbeknownst to us. His wife underwent some kind of surgery and was now in the rehabilitation and health centre of Tacoma Pastures. Because of some Medicare issue, they could not be in the same room together. Brad's wife needed skilled nursing, and he suffered from dementia. There was no room in Tacoma Pastures that could accommodate both of them together financially. As a result, Brad was left in Memory Care, with the understanding that he could see his wife whenever he wanted. Unfortunately, this was not the case. Because the caregivers could not leave Memory Care for long periods of time, someone from social services or the recreation staff had to take Brad over to see his wife. This happened only once every third afternoon. Brad and

his wife had a son who lived nearby, but because he was working fulltime, he was not always there to take his father over to the rehabilitation and health centre. The situation was very unsettling for Brad. He often complained loudly saying, “What kind of life is this? I can’t even see my own wife?!” As time went on, Adorna started talking to Brad. She did not talk about his wife, but about trying to relax. I heard her say to him, “Brad, you just got to wait it out. Here have a seat.” Brad did not seem to care about Adorna one way or another, but Adorna certainly felt attracted to someone she could sympathise with. He was lonely and frustrated, and Adorna was as well. One day after lunch, and to everyone’s gleeful surprise, a fulltime caregiver working with me noticed that Brad’s door was shut. We also noticed that Adorna was not pacing around or in the common room asking us a host of questions. I tried knocking on Brad’s door, but it was locked. We called the nurse, and the other caregiver and she opened the door only to find Brad and Adorna naked in bed. The nurse told me to look after the other residents, while she dressed Adorna and took her back to her room. The next week, Brad and his wife moved out of Tacoma Pastures. Adorna did not speak about or recall the episode, although no one ever asked her about it.

* * *

In Memory Care, the caregivers were more often than not unwilling to help their fellow counterparts. Caregivers were preoccupied with their own tasks, hoping to finish in time so that they could take their full breaks. Also, the fulltime caregivers were preoccupied with controlling their own section, and asserted power in order to keep other caregivers from criticising the way they treated their residents. In her ethnography of a nursing home facility in New York City, Nancy Foner found that caregivers did not report the mistakes of their colleagues to the nurses. This was viewed as a form of worker resistance to management. Furthermore, Foner found that when aides and caregivers did report serious mistakes and neglect, it was usually problems arising from a previous shift. According to Foner, “The no reporting rule operates primarily among workers on the same shift” (Foner 1995, 134), and “On their own shift and on their own floor, reporting another worker is viewed as treachery” (Foner 1995, 134). In Chapter 8, I will discuss an incident of how I was involved in a situation where a fellow caregiver squealed on me in Memory Care, and how the management at Tacoma

Pastures received this. For now, it is important to note that caregiving is a contentious topic. To cite Foner again, “In the nursing home, where people, not machines, are involved, informing on co-workers usually means telling about the way they treat patients” (Foner 1995, 134). The defensive posturing in which caregivers on the third floor took on vis-à-vis each other reinforced the overall atmosphere of control, and ultimately ownership over the residents, and the system of care that was enforced upon them. Care was more than just feeding and clothing the residents, but about taking them out into the living and dining rooms in a presentable manner. Out in the open, caregivers kept an eye on *their* residents, marking out particular territories, bodies, and work, which demarcated the field of care within a social network of power and dependency. When things did not go smoothly for the caregivers, as in the case of Anita, they could blame a variety of external reasons, including the GP’s decision to change a resident’s medication, or even the occurrence of a full moon.²¹

The caregivers kept an eye on the residents by taking them out of their rooms in the morning, and corralling them throughout the day. The residents were placed under collective watch in the dining and living rooms. A kind of paternalism took hold in Memory Care. Caregivers often forced meals and showers upon their residents; the issue of nutrition and bathing took on a dimension of urgency. Caregivers thought that the residents could do harm to themselves, and so watchfulness and constant engagement with the residents, i.e. keeping them occupied in their stationary seats with music and television, and taking them to the toilet every hour and a half, were deemed necessary aspects of care.

The residents in Memory Care are more than just their bodies; they extend ontologically beyond the confines of their rooms. They did not formulate the difference between good and bad care, nor did they express any explicit definition or conceptualisation of care. Rather, residents resisted certain care regimes. Many of the residents were confused when they woke up. They wondered why they were up on the third floor: “Who is the stranger (caregiver) hunching over my bed?” This is not a moot point, but rather speaks to the violent change that some of the residents who suffer from dementia feel

²¹ Every other month, the caregivers complained that the residents were acting up and becoming unmanageable. Many of them said, “They are all crazy. It’s that time of the year. Whenever there’s a full moon the residents go mad.”

everyday. They sense that something is off, but they cannot quite put their finger on it. They are not passive receivers of care, but view their caregivers as informants who can potentially tell them something about where they are, and what they are supposed to be doing.

Chapter 4: Independent Plus: Care on the 4th Floor

Caregiving is a vague and fraught term connoting images of the frail and elderly on the one hand, while on the other designating a list of medical products, technologies and services in support of the activities of daily living (ADLs) and the occupational therapy needs of long-term care facility residents. Caregiving as a normative conjures up acts of transcendent love, family responsibilities, and intersubjective/morally-inflected relations. The practice and discourse of caregiving bring together and conflate cultural concepts such as autonomy, duty, dignity, self-reliance, self-care, and philanthropy in an experiential framework—especially in organisational settings like the CCRC which are from one perspective ‘factories of care’ and from another sites of new homes and ‘kinscapes’ (Atkinson et al. 2012) This chapter explores how residents negotiate care and make sense of how care is performed on them. By providing a brief discussion of the layout of the fourth floor, the ethnographic vignettes of various residents and their interactions with the caregivers, and each other, will shed light on just what constitutes care.

* * *

It was only after a short period of time working on the third floor that I was assigned to the fourth floor. I took with me some of the techniques I had already learned from my time in Memory Care. For example, I knew how to approach residents, how to organise my tasks around the clumsy wheelchair—including how to help residents who were less than mobile stand up from their wheelchairs—and to transfer and swivel them onto the toilet safely and effectively. From my working experience on the third floor, I was already conditioned to treat routines as frameworks, which needed to be adapted on a daily basis. Something new and unpredictable was always happening. A resident might have a fall, or display a different mood, changing the time required to assist that resident. More importantly, changes in situation affected the planning and sequencing of how I worked with residents in a particular section. At the end of the day, there was only so much the caregiver could anticipate. A stomach virus might work itself through the

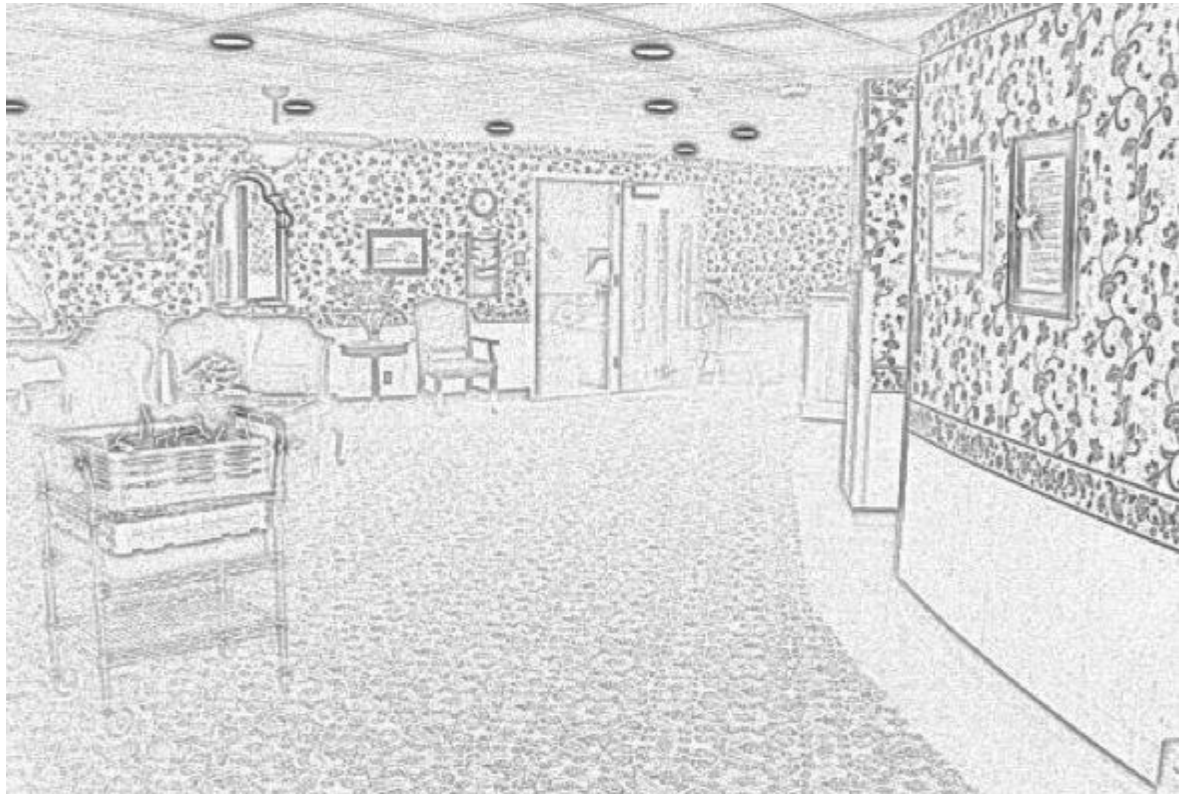
entire section overnight, creating additional tasks and worries. Assistance with dressing and toileting had to work in conjunction with taking urine samples, and even spending more time with residents and family members as warranted by any given situation. In this way, the field site never became one-dimensional even halfway through my fieldwork. Nothing was repeated in the exactly same way. The caregivers found this dynamic very stressful, but it also became a sense of pride. One of the caregivers related to me that she thought the management undervalued her work; she was “overworked, overlooked and underpaid,” but was happy that she did not have a desk job. Such statements do not necessarily entail that the workers were immune from de-skilling. In fact, the point-of-care laptops were widely criticised by all the caregivers. They felt that the old way of charting tasks and observations for each resident at the end of the shift was much better than having to fill out a computer generated questionnaire multiple times during the shift. One caregiver described the point-of-care system as, “The management are finding new ways to keep track of us and not the residents. This is crazy. We spend more time on the computer than with the residents. They have it ass-backwards!” Having said all of this, the caregivers still preferred to have a sense of calm and order throughout the day. Emergencies, such as when a resident fell, or became very ill all of a sudden, threatened the appearance of order and calm that the caregivers valued. So much of their caregiving work was related to getting the residents groomed and dressed for meal times, that presentation and appearance became an indicator of good care.²² In her study of a nursing home in rural Oxfordshire, Jeanette Davies noticed something similar going on. She found that, “Within the habitual routine of the care assistant, the needs of residents were anticipated and met, at the same time that a conversion from disorder to order occurred, from a bedroom state to a publicly accepted state” (Davies 2007, 132). Davies goes on to say about the care assistant that, “[...] their ability to deal with many challenging and sad situations gives them a sense of value that, even when it is undermined by management, remains evident in their approach to work and the way in which they carry it out” (Davies 2007, 132).

²² Jules Henry makes a similar yet different point when he asserts that, “The social conscience is affected by things having ‘high visibility,’ like clean floors, freshly painted walls, and plenty of medical supplies, rather than by those having ‘low visibility,’ like personal involvement” (Henry 1963, 393).

Although the fifth floor is an “independent plus community” at Tacoma Pastures, I will focus only on the fourth floor, where I spent most of my time working as a caregiver. The fifth floor residents did not require much help, but there were residents who did require help, but from just one caregiver at a time rather than two. I worked on the fifth floor as well, and there were some differences, but not significant enough to warrant a fuller treatment. It is useful to say, however, that only two caregivers were assigned to the entire fifth floor per shift. There were fewer call buttons going off on the fifth floor, and most of the residents did not need any help showering and/or toileting. There were exceptions, and the residents who needed assistance were able to spend more time with their caregivers as opposed to the fourth floor. The tasks on the fifth floor were more spread out and ad hoc in nature. When I worked on the fifth floor, some of my duties involved accompanying residents and their spouses to medical appointments in the city.²³

²³ It is perhaps useful to note that the physical layout of the fifth floor is quite similar to that of the fourth floor (see figure 7). There are some interesting differences though. For one thing, residents do not congregate or sit around in the common areas. A small living room, without a television, is never used by the residents or the caregivers. The care plans and the point-of-care laptops that caregivers use to document their various tasks and assessments of the residents are purposively kept out of sight in the caregiver’s small office. The residents’ rooms are never left open; they are always shut. Also, the residents on the fifth floor do not have kitchens in their rooms, and the views from many of the rooms are impressive, overlooking small forest preserves.

Figure 7 The 5th floor lobby area

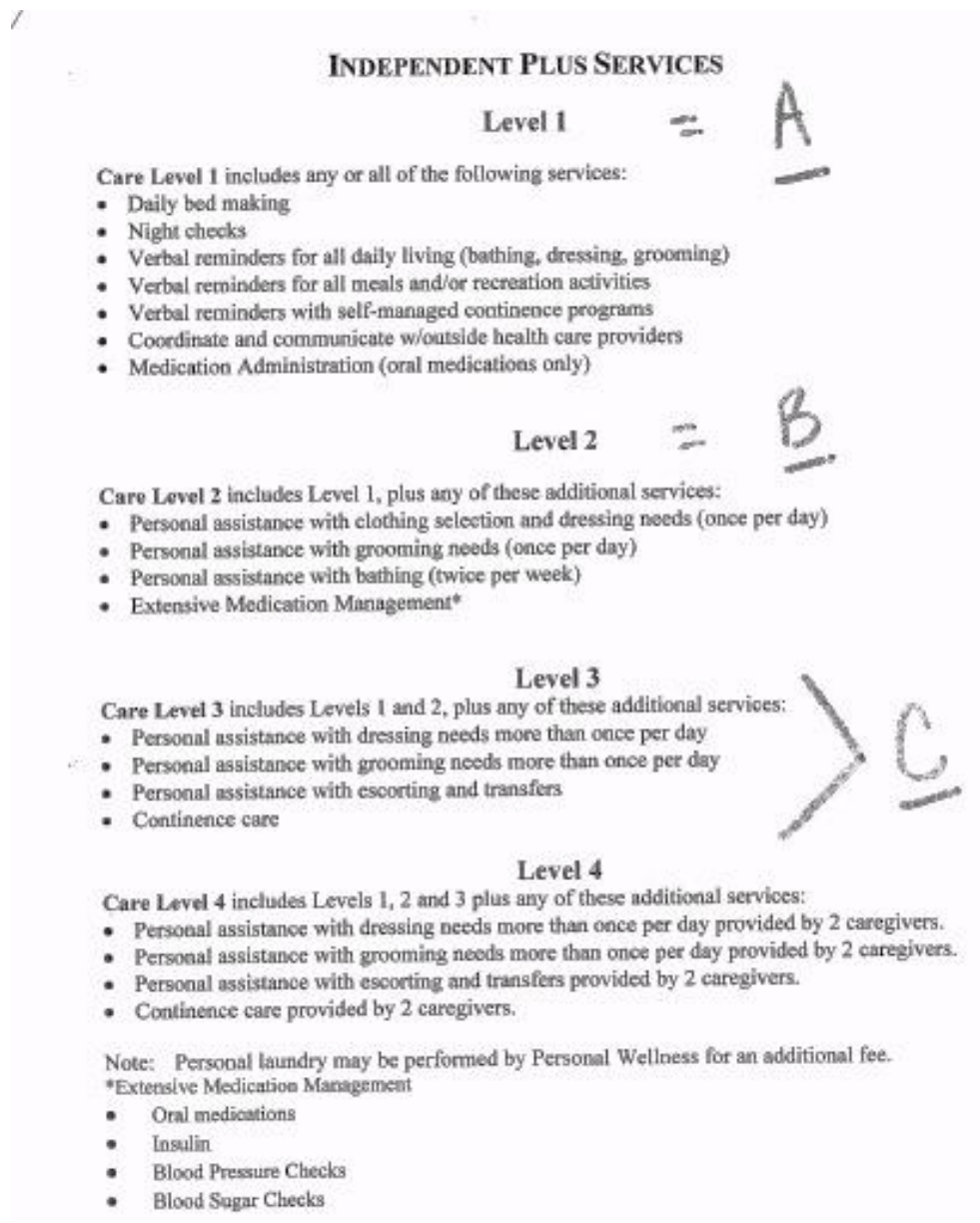


The 4th Floor Layout

Unlike the third floor, the fourth floor is busier. Residents on the third floor rarely pushed their call button necklaces. On the fourth floor, residents pushed their call buttons regularly. This meant that caregivers were always rushing between rooms to attend to call buttons in addition to doing their routine tasks. Because of this, it felt that each caregiver was assigned to look after twenty people, when in reality they had to help about a dozen. Some of the residents pushed their call buttons for specific requests, like finding out how to use the telephone to call their daughter, or to get a caregiver to help them use the toilet. More often than not, many of the residents pushed their buttons, because they wanted someone to just show up and engage with them. Caregivers followed the various care plans and each of them had a list of tasks to perform that they routinized. Therefore, they did not welcome these call buttons. Attending to ad hoc requests, and returning every ten minutes to someone's room, because they simply sought attention, added to the overall stress on the fourth floor. Some of the residents on

the fourth floor did not need much help. In each wing, there was a handful of residents that could get themselves up, dressed, and to the dining room. Some of the other residents were in wheelchairs and needed help transferring in and out of the bed. Other residents on the fourth floor were over ninety-five years old, and needed assistance with all of the activities of daily living. Some of the residents on the fourth floor also suffered from mild dementia, but they were not labelled or considered wander risks. Residents paid for different levels of care, even within the independent plus domain of the fourth and fifth floors. Residents who needed more assistance and required two caregivers had to pay more per month. For the majority of the residents on the fourth and fifth floor, they were assigned to Level A and B care (see figure 8).

Figure 8 Levels of care for the 4th and 5th floors



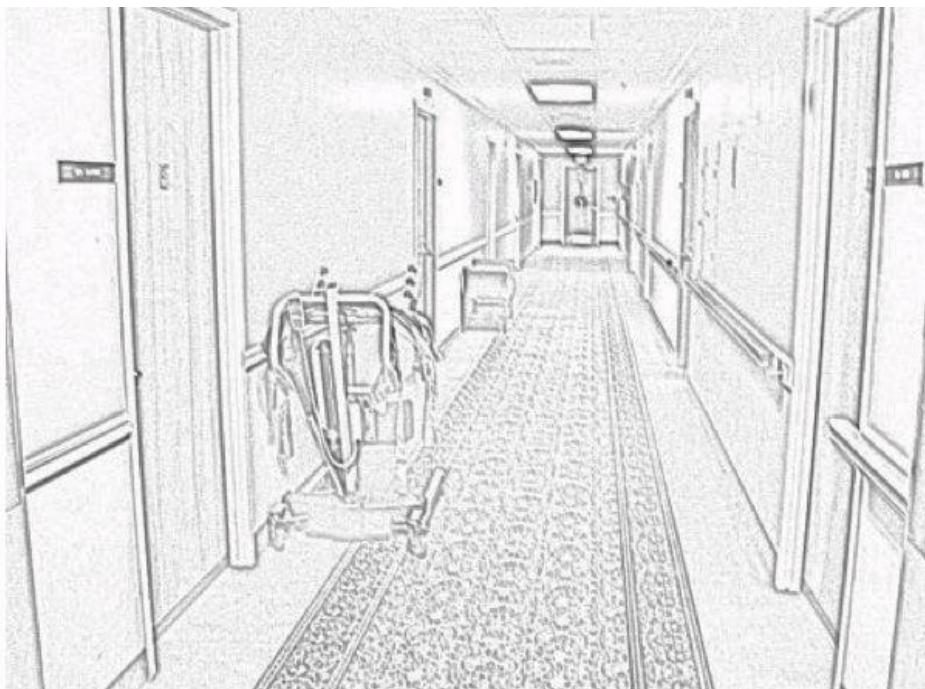
A total of three caregivers and one med tech worked on the fourth floor at any time. Whenever a caregiver called in sick, and a replacement couldn't be found in time, two caregivers had to work the entire floor. This meant that each caregiver had to look after sixteen residents. The main nurse's office was also located down one corridor of the fourth floor, which added to the traffic flow. Throughout the day, nurses, med techs and caregivers could be seen coming in and out of this central hub. The fourth floor had one medium-sized dining room with a toaster, an industrial dishwashing machine, a microwave, but no oven or stoves. All of the food was cooked in the main kitchen on the

main floor next to the spacious formal dining room. Some of the residents preferred to eat in the formal dining room downstairs; those that were in wheelchairs required caregivers to escort them downstairs. Upon finishing their meals, they would push their call button necklaces, and an alert would buzz on the caregiver's belt-clipped pager. Taking people up and down during mealtimes, also added to the traffic of people getting on and off the five-person elevator. There were considerably more visitors coming to the fourth floor than any other floor. Family members often spent several hours with their loved ones in the late mornings and afternoons. Caregivers would talk to family members about how the residents were doing in general, and whether they thought the residents were active, happy, and healthy. Family members and friends who came to visit also brought with them new supplies for their loved ones, such as new hearing aid batteries and clothes. Across from the dining room, a living room area with a small television and an upright piano offered visitors and residents a comfortable sitting place. Residents only used this space during informal events such as music hour; for the rest of the time, the caregivers used this space to enter in data on the point-of-care laptops. Care plans came in two forms. Firstly, there was a binder that listed a summary of the main tasks to be completed for each resident, including information such as allergies, shower days, appointments, dietary needs, and preferred times of waking up and sleeping. The same care plan along with other details, such as mood, and type of BM (bowel movement) in a radial button survey form had to be answered for every resident per each shift. Point-of-care laptops attached to an adjustable wheeled cart were used for entering information as part of the caregiver's job (see figure 9 far left-hand side). Unlike the third floor, there was a small coatroom for the caregivers. Leaning against the corridor walls, one could easily spot a lifting Hoyer (see figure 10), used to transfer some of the residents in and out of bed, and onto the toilet or transportable commode in some cases.

Figure 9 The 4th floor lobby area and Point-of-Care laptops



Figure 10 Picture of a Hoyer-lift in resting position



Caregivers are constantly being trained on new techniques and procedures for charting information and incorporating new medical devices into their practice. They had to

grapple with mechanical E-Z stands and Hoyers, harnesses, measuring devices such as thermal scans and digital blood pressure reading instruments. While these devices are intrusive, the CCRC's management maintains that these technologies are in line with making the residents feel more serviced and comfortable. One director said to me, "These technologies are here to help us give our elders continuing care and service; this is what is most important to them and their families." What gets lost in this is the depersonalization when machines and computers start to substitute for caregivers, and take over the people they are supposed to care for. The caregivers I worked with frequently stated that what matters is the personal touch and face-to-face interaction. There is a prosthetic-environment that one works with, and this really became apparent to me when I used a mechanical lifting device to hoist up a resident in mid air, suspending them like a cyborg detached from their robotic exoskeleton.

The residents' rooms were on average about twice the size of the rooms on the third floor. The carpets on the fourth floor were floral and older than in Memory Care. Additionally, the lighting in the hallways and in the rooms was less fluorescent and much softer, giving the fourth floor a homier and less clinical feel. Also, about half of the residents' rooms on the fourth floor were left open throughout the course of the day. The fourth floor was divided into three sections, and one caregiver was assigned to each section. In addition to the caregivers, one med tech also worked on the fourth floor, administering pills and insulin injections. The med techs did not have a desk, but rather a med cart which they took with them down the various hallways (see figure 11). On several occasions, especially when a new caregiver was working on the fourth floor for the first time, a floater position was created, which meant that four caregivers were working simultaneously. In each section, there were about twelve residents to attend to; only some of whom needed help with transfers. Caregivers entered their rooms, and helped them move from their beds to the wheelchairs and subsequently onto the toilet.

Figure 11 A med cart



One of the residents I worked with named Grant anticipated all the various actions I performed on him. He would instruct me everyday on the same set of procedures he wanted done, even though I had already been assisting him for two months on a regular basis. At 6:15 a.m., he was already awake, and insisted on being the first person I tended to. His door was always cracked open, and before I could even enter his room, he was already speaking to me. Grant said, "Hey, look who it is. Well come on, get my shoes and bring the wheelchair." He had a habit of wanting a fresh shirt on before anything else. Upon picking out a shirt and helping him put it on over his head, he asked for lotion to be put on his legs. He typically wet his briefs overnight, but rather than wait for me to take him to the toilet to get him changed and wiped clean with some of the disposable wipes, he wanted lotion on his legs first and foremost. As soon as he was off the bed and into the wheelchair, and even before I could position the wheelchair towards the bathroom, Grant would lift his right leg up. This was a sign for me to put on his socks and shoes. Once he was on the toilet, he told me how much toothpaste to put on, and then started joking around with me. Knowing that I was just a part-timer, and that I was not always assigned to his section, he would say, "So, I see you've found some more important people to be with."

Grant was not the only person who clamoured for attention. Many of the residents wanted the caregiver's sole attention. Marcy was one such resident. She was not in Grant's section, but she also wanted to be taken care of first thing in the morning. Whenever I passed her throughout the day, and when I wheeled someone back to their room and forgot to say hello to her, she would get upset and let me know about it later. Without exception, Marcy would always push her call button at 6:00 a.m. She was one of the first residents to wake up. I passed out fresh cups of water before 6:00 a.m., and sometimes I discovered that one of the residents in Marcy's section needed help immediately. This usually occurred when a resident had dirtied their briefs overnight, and I had to change them right away. This took about twenty minutes, and I had to walk back and forth past Marcy's room, which was the first room in the section. With her door wide open, she called to me from her bed, "Hello. Are you coming or not?" I had to tell her to wait for a few minutes, and that I was busy with someone else. When I finally got to her room, she would ask, "What was that about?" I would tease her and reply, "Well, you know I had to help another resident and I can't tell you because of HIPPA (the government issued privacy rule)." She would laugh and say, "Well, I know everything that goes around here." Not only did she want to be the first resident to know everything that happened on the fourth floor, she also was very possessive about how much time the caregivers spent with her.

In a typical morning, I transferred her from the bed to the wheelchair and then helped her into the bathroom. I then had her grab the bar affixed on top of the toilet roll dispenser, and then hugged her from the back as she pulled herself into a standing position. At this point, I dropped her disposable briefs. With Marcy still grabbing onto the bar and hunched over, I unlocked the wheelchair brakes and kicked it a few feet back. After she was successfully lowered onto the toilet, I turned on the faucet and allowed the water to get warm.

Marcy asked me if there was any news around. I confessed, none that I was aware of. She said, "I find out everything eventually." As soon as I had wiped her face with a hand towel soaked in warm water, I handed her a toothbrush, and squeezed some paste on it. When she was brushing her teeth on the toilet, I went into her room, and quickly made her bed, and picked out an outfit for her including fresh socks. I came back to the bathroom with her clothes and shoes. I put on her bra, blouse, sweater, pants, socks and

a new disposable pair of briefs. I untied her shoes loosely, and slipped them on her feet. I helped her up, and with my latex gloves still on, I had her stand up grasping the bar, and wiped her bottom three times with three separate disposable anti-bacterial wipes. After bringing the wheelchair next to the toilet, and engaging the breaks, I pulled her briefs and pants up and lowered her onto the wheelchair. As a finishing touch, I combed her hair and offered her her glasses. Before we left the room, I took off my latex gloves and threw them away in the wastebasket right beside the door. Marcy wanted to be positioned strategically in front of the dining room where all three sections merged. She told me that from this position, she could wait for breakfast and keep an eye on things.

An episode occurred involving Marcy and her two neighbours on the fourth floor. Julia lived in between Marcy and Bridgette. Julia had difficulty with mobility, but she still had upper body strength and did not require that much assistance. She wanted only female caregivers, however, in her room. Gretchen, one of the fulltime caregivers, was assigned to her section and told us that Julia was a “one-person assist” and that, “I really just help her with her showers; I make sure she doesn’t slip and fall.” Bridgette was another early riser, and even though she preferred using her wheelchair to move about, she could stand up for few minutes at a time. She wanted female caregivers to help her with her showers, and did not need any help going to the toilet. Whenever I was assigned to Bridgette’s section, she just wanted me to make her bed. When I first encountered Bridgette, she called to me from her wheelchair in the common area. I came up to her and asked if I could be of any assistance. She said, “Did you make my bed today?” I said, “Why? Yes.” She then made me follow her to her room, and pulled off her top comforter, exposing a corner I did not tuck in as tightly as could have. Bridgette told me about how she was a nurse, and that before she could work on bodies she had to learn how to make a bed properly. I apologised and made her bed correctly in front of her. She thanked me and pointed to a chair of stuffed animals and a couple of dolls. She said, “You can display them however you want, but I’d like them on the bed after you make it everyday.” Bridgette wanted her bed made neatly and perfectly. We turned this into a game of sorts; she would ask me if I made her bed and if so, did I do it well. I responded by saying of course, and she would give me a pat on the hand and even offered me chocolate sometimes from her pocket as a reward.

The situation involving these three women changed, however, when Julia started moaning and groaning throughout the day and well into the night. When I first got to know Julia, I noticed that she did not talk to anyone. She interacted with the med tech and some of the caregivers, but she never spoke to any of the residents. I often heard Julia on the phone with her son. With her door open, I sensed that she was happy and quite engaged with her son over the phone. Gretchen told us later that Julia desperately wanted her son to take her away from Tacoma Pastures. As it turned out, Julia's loud moaning and groaning grew more intolerable. She sounded like a wounded wolf in the desert and started to keep Marcy and Bridgette up at night. When I came to help get Marcy up in the morning, Julia was soon wailing. Marcy said to me, "I wish she would just shut up." I came to learn from one of the other caregivers that Marcy and Bridgette's family members called Tacoma Pastures to complain. The nurse attempted to talk to Julia about the situation, to see if she could control herself more, but from what I saw, Julia told the nurse to get out. Another week passed, and I noticed that Julia's door was closed. I asked the med tech what happened to Julia, and she said that Julia was moved to a geriatric psychiatry unit in a local hospital. Jules Henry once described the nursing home as an institution that established a culture for defining its residents in a particular way. According to him, "Every institution thus establishes a culture in terms of definitions of its inmates as special kinds of entities, and in terms of [...] the inmate's capacities for seeing, hearing, and understanding" (Henry 1963, 418). Julia's wailing proved too much for the caregivers, nurses, and other residents on the fourth floor. As a result, they took her behaviour as an indication that she was no longer sensible. According to one caregiver, "Julia just lost it one day." This enabled the caregivers and the head nurse to challenge Julia's competency; her mental health and soundness became justification for sending her away, and very likely contributed to her narcotising final days in the geriatric psych ward. Although Tacoma Pastures is not quite what Jules Henry coins as a pathogenic institution, Julia became a victim. The nurses and caregivers questioned and challenged Julia's judgment, labelled her "a nuisance and a mad woman," and this in effect caused her to lose confidence in herself, exacerbating her irascible condition.

After about a month, I saw Gretchen coming out of the nurse's office in tears. She learned that Julia passed away in the hospital. Gretchen said to us in the caregiver office later

that day, "They killed her. All she wanted was to be taken home, to be with her son, and they drugged her up and killed her." The next morning I entered Marcy's room. I brought up the subject of her neighbour. I said, "Isn't that a shame what happened to Julia? How do you feel?" Not surprisingly, Marcy already knew what had happened. She answered, "I don't feel anything." I raised my eyebrows and continued, "Isn't that sad, isn't that mean?" Marcy looked up at me from her wheelchair and declared, "No, that's not mean. She did not have consideration for others while she was here, and to be honest she was not really living, she was just existing." I asked, "What's the difference?" and got no response.

Heather

Heather's room was located towards the end of the hallway in section three. She was originally on the first floor, but moved to the fourth floor after her husband passed away. Many of the caregivers did not enjoy working with her, because she was extremely particular about how she wanted everything done. In addition to this, many of the female caregivers complained that Heather did not like them, and insisted that she preferred male caregivers. My first encounter with Heather occurred when I noticed that she was listening to audio books. Even though her door was closed, her audio book player was on full blast. She lost hearing in one ear, and was almost deaf in the other. She sent out for the federal government's free library service, which was established by an act of Congress in the early 20th century. The talking books she played were always fictional-biographies, and sometimes the caregivers would chuckle at some of the sex scenes being read, especially as they resonated loudly at the end of the corridor. When she was in the dining room on the fourth floor, Heather wanted her placemat and cutlery arranged perfectly and symmetrical; there had to be right angles for everything. Brendan, a pre-med student and male caregiver who worked in her section got along very well with her. He advised me how to work with Heather the first day I was assigned to her. He shared with me his techniques and strategies. Brendan said to me, "She likes male caregivers, so you'll be ok. She feels more secure when a guy transfers her. Don't be intimidated. She's from Washington State and has a hard shell, but once you get to know her she is very sweet. What I do is get up close and speak to her directly. Look into her eyes. I also repeat myself and reiterate things a lot. I think she likes this confirmation."

Brendan escorted me into Heather's room and introduced us to each other. I witnessed how he squared himself in front of Heather, and spoke to her in a fairly loud voice. He even leaned towards the left ear at times to make sure that she understood him.

I started working with Heather at least three times a week. She wanted to be woken up at 8:30 a.m. everyday. When I arrived in her room, and after giving me a tutorial on how I should fold her bed blanket back so that the corners were perfectly in line with the end of the bed, she instructed me on the angle she wanted to be propped up in bed. It took more than a minute to achieve her desired angle as I worked the electric adjustable bed buttons. As soon as she was satisfied with this, only then could I bring her wheelchair next to the bed to begin transferring her. Heather also had a particular set of routines she wanted observed in the bathroom. After helping her onto the toilet, I was to use the right towel on the rack for washing her face, and then the left towel for her legs. She didn't mind that I left the faucet running a bit to achieve a warm temperature for soaking her hand towel, but she did want the towel squeezed several times. She asked me, "Did you do it many times?" I reassured her loudly into her left ear. She nodded. As soon as I wiped her face, and grabbed another towel which she wanted draped over her, without one side dangling more than another, like a perfectly donned hair salon apron, Heather wanted me to put a pea-sized amount of paste on her toothbrush. She enjoyed brushing her teeth for literally ten minutes. If I came back to the bathroom any earlier, she would still be brushing and would not surrender her toothbrush. After I lowered her bed and made sure that the small blue bed spread was not stained or wet, I made her bed with gruelling precision. Afterwards, I re-entered the bathroom and stood next to her for another three minutes, while she finished brushing her teeth. As soon as she was finished, I gave her a small plastic cup to rinse her mouth. At this point, she handed me the toothbrush, and before I could finish getting her dressed, she watched me carefully as I rinsed her toothbrush. She wanted me to rinse her toothbrush under the faucet for a good two minutes. This was also one of her requirements.

I am recalling this in detail, because Heather was unique in the way she wanted everything done. She wanted things folded in a particular way, and whenever I transferred her back to her chair after breakfast, she wanted to sit right up against the back of the chair. More than this, she wanted her smock completely wrinkle free in the back. Because of this, transferring her always took more than one attempt. The other

caregivers who did not listen to her or left without sitting her down properly would be chastised; she would push the call button over and over again, and sometimes the nurse would have to come and help. I recognised early on during my interaction with her that she might have some form of obsessive-compulsive disorder (OCD). I was sympathetic to this and had to explain to the other caregivers that Heather was not a control freak, but perhaps suffered from OCD. The other caregivers thought she was bossy, and many of them even called her a “mean bitch.” I told the other caregivers about her possible condition, but none of them seemed to really care. They still held to the belief that she was mean and someone they did not want to work with. One caregiver said, “She’s just so bossy, and she is always pushing her call button.”

In addition to her loss of hearing, Heather was also partially paralysed on the left side of her body. Despite this, she was very observant, and able to control her immediate environment and particularly how she wanted things arranged on the bed, on her chair, in the bathroom, and in the dining room. One day, Heather complained to me that she was still not happy she had to move from the first floor. I asked her why she had to move and she replied, “They made me do it. This is not ageing in place. I am still struggling with adjusting to so many new things.” I got on well with her, even though she took extra time and energy. I had to tell her constantly that things were straight, even, and symmetrical. She wanted things wrinkle-free, and I did the best I could to put her at ease. Near the end of my fieldwork, and after working with Heather for more than half a year, I noticed that she had an old radio. I asked her whether or not she would like to listen to music. She told me that she did not like music. She said the radio was broken, and that she and her husband used to listen to the news on the radio together. Additionally, I found out from her that her deceased husband received his PhD in journalism from Northwestern University. I asked her if I could take a look at the radio and maybe fix it. I took the radio after work and found out that someone had plugged the power chord into the wrong hole. I returned the next morning and tuned the radio to an AM news channel. Heather was extremely excited and said to me, “You have brought me the world. It’s been years since I listened to the news. Thank you.”

Teri

Teri was a resident in the same section as Heather. She had been on the fourth floor for more than five years, and was the widow of a former Air Force Officer. Teri had a son who lived in a nearby state, and a daughter who lived just ten minutes away. Her daughter and son-in-law came to visit once every month. On one occasion, her daughter came out of the room with tears in her eyes. Her husband comforted her while she said to me, "Thank you for looking after her." I then heard her say to her husband, "She only ever loved Jack." During the Christmas holidays, I also met Teri's granddaughter for the first time. Teri was younger than most of the residents, and according to one caregiver, she had travelled the world with her husband, and was not much of a mother. She always talked about her son Jack, and would forget that her daughter had just visited her, even a few hours after the fact. Teri was really fond of one particular caregiver named Elmira. Because Teri was heavy and bedridden, she required two people to help her. I came to assist Teri whenever Elmira pushed Teri's call button. Teri never ate breakfast, and preferred to wake up at 10:00 a.m. This was okay for the nurses and the caregivers, because 10:00 a.m. was a good time; the residents were just finishing up their breakfasts and no one else had to be dressed. Unlike the majority of the residents on the fourth floor who took their showers in the early evening, Teri did not take any showers. She could not stand in the tub and transferring her to sit on the side of the tub, was also too hard to manage. Therefore, Teri received her bathing in bed, making the most out of a couple of hand towels and a medium plastic container of lukewarm soap water.

When Elmira and I entered her room, she would peer at us from the bed and say, "Where have you been?!" Elmira responded in a joking manner, "Well, waiting for you to get up." Teri would grin and look away. Elmira went to the closet to pick out her clothes, while I went to fetch the mechanical hoist. We wiped her face and then had Teri lean towards one side while we inspected her briefs. She always went to the bathroom in her briefs. Elmira and I put on our latex gloves and reached for the disposable wipes. While on her side, Teri allowed us to wipe her bottom. On many of these occasions she would let out a fart, and Elmira would tease her, saying "Well, something smells, did you do that?" After we wiped her bottom and sprayed her with an antibacterial cleanser, Elmira would say, "Ok, now it's time for you know what." Teri looked stunned and said, "What?!" And to

this Elmira responded, "It's time to wipe your hoo ha." Teri grinned, but a smile soon emerged. After we turned her onto the other side, I took the dirty bedspread away, and she pleaded for someone to scratch her back. I took to this task enthusiastically, mainly because she derived so much satisfaction from it. She could not reach around to her back, and my scratching was a real relief for her, especially after sleeping on a wet bedspread.²⁴ As soon as Teri was cleaned up and dressed, we put some bandages on her legs. She had a skin condition with many warts and rashes, and the bandages helped to protect her sensitive skin from ripping. When Teri finished lunch, Elmira and I would take her back to the room, and check her briefs for signs of any wetness. We slipped a large sling behind her on the wheelchair, fastened it, and lifted her out of the wheelchair. I controlled the lift like a crane operator and slowly lowered her back into bed. Elmira turned on the television and brought some peanuts over to her and placed them in a plastic cup next to her. She would be in this position until 5:30 p.m., when the next shift caregiver would have to change her briefs and take her to the dining room again.

Teri often commented to us while we were wiping her bottom, that she had made a stinky. She would say this tongue in cheek, and confronted the fact that Elmira was disgusted by the smell. Teri would say, "What's the matter?" Elmira said, "Someone made a mess again." She was very aware of her condition, but rather than dwell on the fact that she was bedridden and could not use the toilet or even a portable commode, she allowed Elmira to joke with her about her bodily functions. Whenever we turned her to the side and asked to check on the status of her briefs, she pretended to be surprised and in awe. She announced, "What in the world are you doing?" She joked with Elmira, and asked why I was always there with her. Whenever we took her back to the bed after lunch, she would not let us leave until Elmira tucked her in. Elmira had to kiss her on the head, and pulled her blanket up close to her chest.

²⁴ Caregivers are supposed to check some of the residents' briefs and bedspreads on an hourly basis to ensure that they did not have to lie in their own pee and poop. This rarely happened though. What was most important was for the caregiver to change the residents' briefs and bedspreads just before the end of the shift so that the incoming resident could start the shift on a clean slate.

Lana

Lana lived next door to Teri and had limited mobility. She was even younger than Teri, and not more than sixty-five years old. I never found out the circumstances which led her to move to Tacoma Pastures, but her husband who was slightly older and still living in their home came everyday to sleep with her. Norman slept on the couch and as soon as the caregivers got her up for breakfast and then laid her back down in bed shortly thereafter, he left for the rest of the day. He did not return until 10:00 p.m. One of the caregivers said to me that he had a girlfriend, and saw her whenever he left. Although Lana was very nice and courteous, Norman's presence in the room made all the caregivers uncomfortable. He never left the room when we cared for her, and watched us every minute like a supervisor. He would criticise the caregivers often, and make very disparaging remarks. One time he told me, "Don't you have something better to do. Leave this work to the girls. You're a man, I'm sure you can find something more suitable to do."

Lana couldn't bend her legs at the knees. She required two caregivers to help her get out of bed and to attach her to the mechanical lift for transferring purposes. If Norman pushed the call button, and someone was not in Lana's room immediately, he would make a fuss. He complained to the nurse on several occasions, but the nurse sided with the caregivers and told him that everyone was working as fast as they could, and that there were other residents that needed assistance. Norman frequently said to the caregivers that, "This place is just awful." In the morning, a caregiver would show up in Lana's room and depress her call button. Within a few minutes, I would arrive and help. I talked to Lana while she was in bed and asked her how she was. Norman did not care for too much banter, and would sometimes reprimand the caregivers for talking to each other whenever we were in their room. We swung Lana to the end of the bed and attached a sling behind her back. Using the lift, we hoisted her up, and while she was standing on top of the EZ-stand contraption, we took her to the bathroom. I did this very slowly, otherwise Norman would yell, "Hey, watch the elbows." Because the EZ-stand machine was rather wide and Lana was upright, and holding on to the handles, her elbows were likely to get nicked on the doorframes, which actually happened to her some time ago. We sat her down on the toilet and left there for a good ten minutes. She

wanted to take her time. As soon as Lana was on the toilet, I heard Norman in the background, "Lana, go ahead and empty your bladder." When she was done on the toilet, she pressed her call button again. Meanwhile, Norman was sitting on the couch, drinking coffee, and waiting to offer the next set of critiques and instructions.

We cleaned Lana and put on a new pair of briefs, a bra, pants, socks and shoes while she was still sitting on the toilet. After this, we attached her sling to the EZ-stand and stood her up, whilst pulling up her briefs and pants. We pulled her out of the bathroom, slowly, and into the middle of the room. Picking out clothes was a rather hard ordeal, because Norman wanted her to look pretty. As a matter of fact, Lana always slept with her wig on. I picked out a turtleneck, which was always *de rigueur* according to Norman, and a sweater or sweatshirt of some kind. Frequently, Norman would disagree with my choice and said that it did not go well, or that the top did not match the turtleneck. I turned to him once and said, "Well, what do you think?" Norman said, "I am not a fashion expert, but maybe something in yellow. You work here, you should know this." I rummaged through the closet and found the one yellow sweatshirt she had just worn two days ago and slipped it over her head. Whenever Norman disagreed with the caregiver's clothing choice, he would often offer up his usual, "Don't look at me. Pick out what you think is best that will make her pretty. I'm just an innocent bystander here."

As we lowered Lana into the wheelchair, Norman got up from the couch and inspected her position. He wanted her to be right up against the back of the chair, and if she wasn't he would have us lift her up again and re-position her. Additionally, he often complained that her pants were riding up too high. With sweat in my eyes and half squinting, I huddled over her wheelchair and adjusted her pants while she was still sitting down. Lana often had tears in her eyes, especially when Norman was combative with the caregivers. She would often say to us, "I wish I was better." One caregiver told me that she still didn't know exactly what Lana suffered from, but thought it was some kind of neurological disorder that came up rather unexpectedly. To add insult to injury, Lana contracted a stomach virus one day, which meant that her bowel movements were extremely pungent. We were required to bring in two large red wastebaskets with bio-hazard signs written all over the bags and bin, but Norman was not happy with this and denied that she had anything. He pleaded with the nurse, but the bins were not removed. The head nurse never commented or gossiped about Lana and Norman. She commented

on other residents, but for some reason she did not feel the need to say anything regarding Norman. One of the caregivers who worked fulltime in Lana's section said to me out in the hall as we were waiting for Lana to finish on the toilet that, "Norman is overassertive. He is frustrated and doesn't know what to do with his wife. He is still in denial and because of that he takes it out on everyone around him."

* * *

On the fourth floor, residents were aware that they had to share caregivers, and that no one could monopolise any one caregiver. Within this context, some residents were in competition with others for attention. Some were very vocal about this while others were subtler in the ways they anticipated and expected caregivers to aid them, asserting control over the things they could control. A struggle for attention and for asserting personal domain in light of one's social and physical condition in the face of the caregivers occupied much of the residents' energy. Care became a navigational set of procedures for the residents. For the caregivers, care was about managing residents in various situations and circumstances that arose against the backdrop of resident-resident relations and family histories that came to bear everyday in the daily life world of Tacoma Pastures.

The residents at Tacoma Pastures looked to their caregivers for a variety of things. They wanted someone to appear before them in a timely manner whenever and wherever they pushed their call buttons. For some of the residents, caregivers were people they could talk to, joke around with, appraise, and evaluate. Caregivers provided the residents with attention and a set of ears. Some of the residents viewed the caregivers as custodians of goodwill as well. When I asked some of the residents what they wanted from their caregivers, they often told me that, "A good caregiver is someone who is good at their job, but also friendly and nice." Caregivers often relayed their residents' concerns to the nurses, and in some exceptional cases, to the directors as well. There was never the desire for the residents to dissolve the formalities involved in their interactions with the caregivers. Perhaps it was a sign of their generation that they were for the most part courteous and polite; they wanted communicative formality, as well as something personal and friendly in their care. Whether or not they wanted to or not, they were sharing their experiences of ageing with the caregivers, and part of the

caregivers' job was to maintain their tasks in light of this fact. Not all residents wanted caregivers to like them, but many of them did. They wanted to make caregiving socially meaningful in the sense of having the caregivers return to them the following day, remembering who they were yesterday, and what routines they could both orchestrate together.

Part 2

Chapter 5: A Long Way From My Infant Needs: Performances for the Self in Acts of Formal Caregiving

Poems can weave intricate truths, and one truth is this: Humans lie to themselves in order to survive. In his treatment of death and denial, Ernest Becker asserts that man's condition is fraught with certain dualisms. On the one hand, man is an animal yet on another he is a poet. This perplexing dualism underscores the Sisyphean struggle for transcendence both physically and ontologically (Becker 1973). Humans are stubbornly bound by their animality, and simultaneously threatened by this 'reduction'.

This chapter explores how the interactions between Tacoma residents and myself, as a caregiver, illuminate the ways people enact personhood. I will draw theoretically from Ervin Goffman's analysis of the various performances of the self (Goffman 1969) to show how caregiving elicits certain performative acts that call into question the interface between personas and personhood. By focusing on the microsociological interactions that play out during caregiving, I hope to show that persons are implicated in their struggles to evaluate and present particular ideas of a 'self', that are not given *a priori*. Goffman's work on interaction ritual is particularly apropos, because so much caregiving today is motivated, at least in principle, by the organizational and social need to deliver 'person-centered care.' Since the early 1970s, nursing home abolitionist-style movements like the Eden Alternative have operated from the premise that long-term care facilities should be more like homes. Dr. Bill Thomas, the founder of the Eden Alternative, has taken up the mission to re-educate society and introduce a more humane 'culture' of caregiving that treats people as people. While this rhetoric is certainly inspirational and appealing, the exigencies of caregiving and disconnection between principles and practices continue to present an ever-widening gulf on the ground. Turning nursing homes into homes is much more than just an issue of interior design. Bringing in more houseplants and pets, and adding yet another recreational sing-along cannot replace the sense of loss and anxiety that so many residents feel once they make the final move into a long-term care facility. Elderly residents living in such long-term care facilities rarely socialize with each other in any meaningful way. Friends are

hard to come by, because quite frankly who wants a constant reminder of the ailments and loss of autonomy that colour so much of the ageing process? Hence, most of the sustained and meaningful interactions that arise, aside from family member visits, come about from the relationship between a caregiver and a resident. The act of caregiving itself is not just simple 'bed and body work' nor therapeutic companionship (although this does occur), but rather ritual practice. There are boundaries to be erected and upheld, and this happens as a function of what I will explain later on as ceremonial discretion.

The Caregiving Dilemma

Before I turn to some ethnographic examples, a few comments regarding caregiving are in order. Caregiving is becoming more prevalent as a form of service and wage labour in places like the United Kingdom and the United States. As societies grapple with the changing demographics of ageing and longevity, concerns regarding care for the elderly are being pushed to the forefront of public debate. Yet despite the economics of it all, and the concerns regarding how people can meet the rising costs of healthcare in late life, caregiving as a job and social function remains undervalued. Moreover, whether in hospitals or assisted living facilities, elders are frequently dehydrated and neglected. Controversies and mishaps are commonplace, and while we recognize that the lack of basic care is an affront to human compassion, the system continues.

Caregiving takes many shapes and forms. To begin with, informal caregivers consist of family members and/or friends. Unlike their formal counterparts, they are typically not trained, nor are they regulated or held accountable to institutional standards and codes of conduct for the most part.²⁵ Formal caregivers on the other hand, are certified, trained and work for organizations like a long-term care facility. They provide respite and relieve informal caregivers of their duties for a few hours each day. Even part-time hospice-workers who make house calls are regulated, trained, and can sometimes even form labour unions. In either case, caregiving still conjures up a gendering of roles and is

²⁵ The division between formal and informal caregiving *as work* is less straightforward. Many formal caregivers started off first as informal caregivers. Additionally, informal caregiving is becoming more visible (in the political economy) now that it has a professional equivalent.

largely associated with the domain of domestic work. As such, working on and touching the body carries a stigma; it is unglamorous work. A caregiver's work is never done; s/he shops for food, cleans, pays the bills, gives medicine, assists with going to the bathroom, dressing and eating, and provides company and emotional support. While people continue to regard caregiving as an important yet undervalued aspect of life and work, family members remain ambivalent about their roles. To this extent, caregiving has functioned as a commentary on the nature of modern kinship, and the failure of the family as an institution to provide care and comfort for the elderly.

Formal caregiving is much more than a transaction of services; time, love and empathy become commodities in their own right. To complicate the picture even more, organizations were once thought to be in contrast to the non-bureaucratic forms of social life, yet when work and home intermingle in a long-term care setting, the work of an organization and the organization of work alters the very practice of caregiving (Rosen 1991). New meanings and the struggle for personhood are brought into an uncomfortable interpenetration. The formal caregiver is afforded an official and authoritative status that prefigures the way s/he comes into contact with a resident. Yet, the formal caregiver soon runs into a dilemma. Idealized notions of quality and person-centered care are indexed to idioms more in line with traditional accounts of kinship and the expectations of what having a family means. The love, commitment and empathic work that ideal caregiving demands means that there will be some natural pushback and avoidance from formal caregivers who are not family members. Formal caregivers more than informal caregivers armour themselves in various avoidance rituals so as to defend against any counter-transference.

The point is not that caregiving elicits existential anxiety, nor that formal caregivers provide bad care because they are not family members. Rather formal caregivers care about things that are shaped by the structures and rules of the institutions they operate in. It is these structures and the articulations of ceremonial interactions that I will analyse in this chapter. For now, let me say that the bond that forms between a formal caregiver and a resident is one of intentional balance. Caregivers share (and intrude into) an intimate space with the people they take care of; they shower and help them with some of the most basic bodily processes. The communicative aspects of aesthesis do not assume that there will also be a sharing of emotional and intentional worlds.

Therefore, bonds are never fixed and they are never complete. Caregivers operate from their cultural understanding of what it means to be a person. The idea that persons are autonomous and have boundaries that need to be respected means that privacy becomes an issue. Perhaps this is in line with Janette Davies' discussion of the habitual routine of care assistants (Davies 2007). For Davies, the ability to turn the 'bedroom' state of a patient to a 'lounge standard' fit to be on view, was "integral to the identity and work role of the care assistant" (Davies 2007, 132). Thus, caregivers work hard to reinforce the idea that their residents should be as independent and autonomous as they once were. It is the caregivers who keep bodies in order, and maintain the appearance that all is not lost. The caregiver must prevent bodies from doing what they do; residents are not allowed to 'let themselves just go'—there is a battle against senescence and entropy. All of this happens intersubjectively. While most caregivers do not reflect on what an ontological process of becoming and existential learning might be for the elders, they are nevertheless certain that what they are working on is fighting against the *unbecoming* of a person. Their residents need to dress properly, to take regular showers, and to remember important things about themselves. The slippage into an inchoate is not an option for residents in the hands of formal caregivers. It is essentially this tension that makes it hard for principles and practices to square with one another in caregiving.

For Arthur Kleinman, caregiving is not a moral duty per se of family members, but those who engage in caregiving do so necessarily as an existential moral experience (Kleinman 2010, 26). Caregiving is not just about how we come to dignify and think about others, it also involves introspection. Drawing from Henry James' writings on the divided self, Kleinman seeks to show that caregiving has been neglected to some extent by modern biomedicine. In fact, Kleinman points out a common criticism: Do our doctors and GPs really care about us and our wellbeing? Kleinman presents caregiving as a mode of being in the world with others, and says that, "What starts out as caregiving for others becomes caregiving for ourselves" (Kleinman 2010, 18). If moral sensibility is on the wane in modern biomedicine, recuperating caregiving as a moral sensibility will certainly have historical and institutional hurdles and challenges. Can we reveal what is hidden emotionally, without pandering to or wallowing in a reified idea of the 'individual' as a postmodern divided self? Surely, this is not the descent of the subject

into Žižek's ticklish borders between structure and nihilism, or even a caving into the insurmountable gap between the ontological and the ontic (Žižek 1999). Instead

The incompleteness and limitations in caregiving are also inherent in being human and suggest the paradox that becoming more human also means becoming more fully aware of contradiction, failure, and incompleteness in our own lives. Realizing the human, then, is not so much an uplifting story as it is a critical and deep soberness over the fate and destiny of humanity and ourselves" (Kleinman 2010, 18). Rather than treat caregiving as simply a burden or an act of love, Kleinman holds that the presence of being there with someone as a caregiver necessitates that the divided self and experience of that phenomenology "...facilitates (rather than undermines) ...caregiving (Kleinman 2010, 19).

So, what's at stake? Herzfeld reminds us that the politics of care, discipline and suffering have left indelible marks on the body, and that one of the projects of anthropology is to provide a critical response to the structural realities that people confront (Herzfeld 2001). Lambek and Strathern contend that what has become omnipresent not just in hospitals, but in academic 'texts' such as this one, is the body. In part this is due to: "the increased visibility and objectification [of the body] in late capitalist consumer society" (Lambek and Strathern 1998, 5). For Maynard, and following from Lambek and Strathern's understanding of the body against the fiction of post-modernism, the body is becoming a salient signifier again. This is especially true in the case of ageing, as one imagines discarding and exiling the parts of the body that no longer 'work'. The body is "coming to replace the 'person' as a subject of inquiry, and I would add 'identity' as well" (Maynard 2007: 3). This is how I come to understand what one resident said to me one morning when I got him up earlier than he wanted to, in order to put cream on some of his rashes. He protested: "I'm dying and all you care about is my crotch?!"

In the absence of any theodicy, how are we to make sense of new social spaces that provide relief and care instead of regulation and punishment (Herzfeld 2001, 217)? How can an anthropology of care scale down to the level of particular persons and their immediate worlds? By investigating instances of caregiving, I hope to show that my

interactions with residents speak to the way humans deal with suffering and ‘presence’ in the world. If presence is about emotional embodiment and the realization of personhood, then we should not be afraid to destabilize our preconceptions. At stake is the way we reclaim the praxis of caregiving from a normative public space, and start to care about (and for) our ‘being’.

What follows is an ethnographic account of three separate instances of caregiving. Melanie, Mary and Betsy were residents I provided care for on a daily basis at Tacoma Pastures.

Melanie

Upon entering the Red Cedar Memory Care unit, I approach the living room nestled in the middle of the corridor directly opposite the dining room. I notice Helen sleeping in a loveseat. Sonia hands me the beeper and tells me that Helen *just* managed to fall asleep. Helen is fully dressed, from the day before, wearing basic grey slacks, a fairly new pair of black leather Easy Spirit shoes, a red sweater (a Christmas present no doubt from several years ago), and a pair of clip-on earrings. Her makeup is surprisingly intact, except for the red lipstick that always manages to smear onto her dentures. A hospital-issued soaker pad provides a second layering to her cheap pink acrylic blanket. She is fully snuggled. The TV is blaring an infomercial on an age defying skin cream, featuring extracts from an exotic Thai fruit. I turn off the TV, pull up Helen’s sheets closer to her neckline, and keep the shades down.

“How was last night”, I asked?

Sonia is already dressed for the bitter cold, and talks to me as she starts darting for the exit. “Fine. I toileted everyone. Kathy was something else. I think it’s the full moon. She was up and about, shaking and wanting to know what she was doing [here].”

“Oh, did you manage to give Kathy a shower?”

“No, she refused, so I just gave her a sponge bath [on the toilet].”

“Is there anything else I should be aware of?”

“Nope, like I said everyone has been toileted and changed. Have fun.”

“Thanks.”

I go into the back of the 3rd floor dining room kitchen and start filling up cups with ice and tap water, and breaking the straws so that the tips still have their covers on. After the waters are done, I place a cling wrap over the cups that I can't find covers for. I punch in a four-digit code and re-enter my section with my dim sum cart of ice-cold waters, which no one will drink unless I do the 'nursing'. I turn on the hallway lights, and start thinking to myself...winter is not kind; it's cold, icy, more old people die in the winter, and in the morning you just want to crawl back into bed. After all, it's 5:45 a.m. But I'm glad to be inside, and I'm glad to be caring for someone. It's a surreal 30-Celsius inside, and we are isolated from nature's harsh conditions.

I stuff my scrub pockets with a handful of transparent gloves from the dispenser in the hallway, and set my beeper to vibrate. We're supposed to knock before entering the residents' rooms, but these courtesies are only entertained when the Director is around, or when we're training a new caregiver. I scribble down my list of showers to give, beauty shop appointments, laundry slips, and get my vital kit in order. With my gait belt fastened and pen in hand, I start my day of routines.

I enter Melanie's room, and see that her blinds are wide open. It's still dark outside, but I close them. I don't notice any smell, and see that her water also hasn't been touched. I turn on the bathroom light and leave the door halfway open. I empty the cup and replace it with a new one. She is no longer in REM, but I'll have to wake her up. Melanie's soaker pad needs repositioning, and so I adjust her pad and begin to rotate her onto her right side. After lowering the bed with an attached remote, I prop up her head with my hand and adjust her pillow. I reposition her feet, which are in robot-like foam boots. She is too tired to fight me, but I feel the grimaces and annoyance on her face. I slip on a pair of gloves and check for signs of bowel movement (BM) and wetness in her briefs. I feel her front and then slide under her back. She seems dry enough...

Two hours pass and I am back now to get Melanie up for the day. Her day is effectively 4 hours long, from 10:00 a.m. to 2:00 p.m. After 2:00 p.m., I will have to lay her back down changed and on the bed, as per the request of the second shift caregiver. But for now, I am eager to cheer her up. I rummage through her closet to pick out what I think will suit her for the day. I find a pair of denim spandex jeans, a bra, a blue turtleneck, white

jogging socks, house slippers, and a flowery white Christian-inspired Town and Country sweatshirt.

I open the blinds and turn on the radio to National Public Radio (NPR), there's a trumpet concerto playing. How baroque: heaven on earth.

"Goooooooood morning Melanie. How are you?" Silence.

"Let's see..." I take off her blankets and expose a half naked fifty-five year old woman, curled up. I take two small travel size shampoo bottles and place them in her hands. She grabs tightly onto them, but not before grabbing my fingers. I have to apply quite some pressure to peel her off of my fingers, and back onto the small bottles. Sweat is already coming down, and I have to throw away my gloves in order to wipe away the sting in my eyes. I slide on another pair of gloves, and begin taking off Melanie's Velcro briefs. She's had a BM by now, and so I carefully roll her onto the left side. I take the bottle from one of her hands, and guide her to grab the bedrail. She does this, but not before grabbing onto my shirt.

"Melanie, let go!" I turn her over and slip the brief out. I reach for a box of wet wipes and spray her bottom with an antiseptic, and then start wiping from front to back. I go through about five wipes, and then deposit my gloves and the wipes into a nearby black wastebasket, which I will have to tie up and dispose of down the hall.

I put on her bra, with much difficulty, because Melanie does not help at all. Every muscle and position, I have to place her in, like a person juggling with a 200lbs stiff mannequin. Eventually, I get most of her clothes on. But before I pull the wall-chord to alert the other caregiver that it's time to transfer Melanie from the bed to her special wheelchair, I turn on the warm water in the bathroom and throw a rag into the sink. I fold her nightgown, and place it onto the seat of her chair.

* * *

Taking care of Melanie was a challenge. Because of her neurological condition, Melanie was unable to speak and comprehend speech of any kind. This challenge created an initial distance between Melanie and I, which assumed complex dimensions. Our caregiving sessions took on a very tactile and bodily intimacy, and I felt that there was an

insurmountable abyss. The silence was also unbearable at times. I found myself filling in the void by talking to Melanie about the various steps I was about to perform. While brushing her hair, for example, I would provide detailed commentaries as to how I was brushing it, whilst talking her through and during the process. I began to notice over time, however, that my monologic communication stopped, and I was more at ease to be with her in silence. At first, I felt awkward that no one was observing me. With my other residents, they would at least provide direct feedback and I felt as if they were constant observers, keeping me honest so to speak. With them, I had an interaction, some kind of a feedback, a measuring stick. With Melanie, the onus of providing ‘quality care’, took on an absurd dimension. After a few months, I began mimicking her silence and stillness when I was with her. I also noticed that her husband who visited every Wednesday (bringing clean clothes) would often sit in the lobby or in the middle of the hallway in great silence with his head, not cast down, but upright. He mirrored her in an affectionate way, and this comportment also rubbed off on me. Getting Melanie dressed and toileted was labour intensive. When I first started working I had to go to the hospital during my shift, because I sprained my wrist trying to roll Melanie over. In retrospect, I came to see the paradox Goffman once wrote about (Goffman 1967, 81): we dress up patients and clean them in part so that they can present a more favourable appearance (to/of us), and that the work of dignifying occurs oftentimes under extreme indignities.

Gina

Gina lives on the fourth floor in a room halfway down the left corridor. She was born, and lived most of her life in Saginaw, Michigan. In the early 1900s, Saginaw was a major port for the Great Lakes vessels, and the home of various lumberyards and sawmills. But for Gina and her family, they lived through the rise and fall of the automotive industry in Michigan. By the mid-1900s Saginaw had become the site of several automotive manufacturing companies. As Gina would convey to me, most of her memories of making a home and “working hard—without asking for anything in return” were tied to this “stinky little town.”

Gina’s blue-collar roots were reflected most prominently in her flannel shirts and monotone work-wear trousers. In fact, her wardrobe and general no-nonsense approach

to people would give one the impression that she had just stepped out of the shop floor. More than anyone else, Gina was always aware that she was just one of many residents that the caregivers had to look after. Not only did she defer to us, but I also felt that she had deferred perhaps too much to the other residents and their needs.

One particular morning, Gina woke up as usual before I finished passing out my glasses of water. It was 5:45 a.m., and she had pushed her call button. I came into her room, and she told me that she was ready to go to the toilet. I set my beeper on silent mode, and closed the door behind me as I entered. "Ok, Gina. Just give me sec. I have to go and get the lift." I paced down to the end of the other hallway and grabbed the mechanical lifting Hoyer. As I entered Gina's room, I also asked as I usually do, "How are you today?"

Gina replied just as she always does every morning in a wheezy voice, "Just awful...pain." I replied, in accordance to our little ritual exchange, "Would you like me to get the nurse?"

Gina, still wheezing, managed to say, "No, that's alright. I'll just wait to take my medicine after breakfast." Although Gina was technically a 'two-person assist' (meaning that it takes two people to get her up), she was comfortable with just me getting her up out of bed, and onto the portable toilet facing the TV.

Once she was on the portable hospital issued commode, I would offer her a warm washcloth to wipe the sleep out of her eyes. She would then instruct me to find pants with an elastic band (actually all of her pants had an elastic band on them). She also asked for her red flannel shirt. While she was still on the toilet and with the transfer harness vest fastened to her through two plastic black buckles, I ripped off her dirty brief and slid on a new disposable one. I poured some lotion onto my hands, and glided the white liquid with my plastic gloves all over her wrinkled legs. I put on her socks and shoes. When this was done, I attached her harness to the lift's robotic arms, and then lifted her off of the toilet halfway by operating a TV like remote. The lift had to be swivelled around and moved back a few feet from the toilet. While Gina was awkwardly suspended, I moved the commode out of the way entirely, and pulled her pants up properly, which were resting at her feet the whole time. Even though Gina seemed sleepy, she was very observant and aware of the entire process despite having to go through this same routine day in and day out. While suspended, she reminded me that I

had to bring the wheelchair over, closer to the Hoyer, so that she could be lowered all the way back onto the chair. When she was finally in the chair, I took her plastic purple brush along with a few hairgrips, and began to style her hair the way she had taught me during our very first meeting and caregiving session.

While I was brushing her hair, Gina talked about her grandson and how he was getting his PhD in linguistics. She also added that her husband died relatively young. I listened with interest, and began opening up the conversation to other topics. I asked her what life was like here in the CCRC. She said, “I can’t do what I want to do anymore, so I am not living really.” I felt stupid for not being able to come up with any words of encouragement. I thought to myself, she enjoys certain TV shows, has her routine, likes her reclining chair with a blanket thrown across her legs, and has an endless supply of butterscotch hard candies to soothe her throat from the yucky medicine she takes after her lunchtime vanilla protein shakes. She is comfortable, warm, and her sons and grandson visit her often; I felt somewhat relieved by these facts, and also guilty at the same time for conjuring up these thoughts.

* * *

Gina would make it a point to be awake before I entered her room every morning. Upon entering Gina’s room, I would say hello and she would acknowledge me with her eyes, and raise her eyebrows. This was her opening salvo. She would always prompt me to ask her, “How are you”? And I knew her response. She would complain of pain and this would trigger me to say in our ritual exchange, “Everything will be alright. Do you want me to get the nurse”? She and I came to depend on this morning exchange. It was her way of making sure that I still cared about my caregiving, and that we could start the day on familiar ground. Transferring her out of bed and onto the toilet required the use of clumsy machinery; she was quite overweight, and though she possessed strength and command over her body, she used her body as an interface for her and I to exchange vital information about what should and could be done with respect to her comfort, and how she could occupy her space in a meaningful way. In her ethnography about dying and palliative care, Julia Lawton argues that the body is not a docile or sterile object in the dying process (Lawton 2000). Rather, the body and its decay emanate a symphony of signifiers.

I deferred to Gina's body, asking her each time if I could "lift her feet now" or "Can we grab onto the lift?" Her body was not a barrier in our caregiving sessions or the sole focus of our interactions, but because so much manual and physical work was required to move her, a bifurcation soon emerged. It wasn't that her body was an obstacle or diversion; near the end of my fieldwork I actually got quite efficient and good at getting Gina up and out of bed and about. The point is that Gina and the other caregivers, including myself, started to construe a sense of privacy. Gina needed help with ADLs, but after we had performed what was minimal, we left her alone in the name of privacy. One caregiver told me coming out of Gina's room, that she was glad Gina was in her room, and that we could now mind our own business. Fences may or may not make good neighbours, but what we were doing was performing a kind of avoidance ritual. Through our interactions with Gina, we erected fences and boundaries. We constructed a private self, one that put at ease our own ontological commitments at the expense of confronting any real emotional empathy and entanglement. We also made sure that our 'selves' did not get in the way of caregiving. Our deference to privacy constituted an avoidance ritual (Goffman 1967, 71). The ensuing dialectic between avoidance and presentations of the self provided for much of the tensions that structured our dealings with Gina. She was also complicit in this ceremonial discretion. She was conscientiousness in not demanding too much of our time. She would always say that someone else probably needed the lift more or needed more attention. She tried hard not to impinge on our demanding schedules, and to this I would often say, "But Gina, you have to fight for your share around here too. You deserve the attention and our time as well. You paid for it." Gina moved about very methodically. She was somehow always in the back or in the corner of a group photo. Gina was always there, yet not quite present either, looking at us from the side of her eyes. Likewise, we would look at Gina from the side of ours.

Betsy

Before coming to the CCRC, and before the worsening of her dementia, Betsy a grey-haired and slender woman no taller than 5 feet 2 inches was once a professor in human development and human sexuality, a United Church of Christ ordained minister, a roller skater, and an activist. She is a gentle spiritualist now, a widow, and the mother of three adult children. For many residents like Betsy, getting them up in the morning is a long

drawn out process involving a mixture of creative lying and coaxing, the use of elaborate mechanical devices like the Hoyer lift, and the assistance of two caregivers. Over the past few weeks, caregivers have been less than enthusiastic about coming into Betsy's room. Her recent bout with C.Diff (Clostridium Difficile) turned the room into a biohazard zone. Caregivers enter her room with masks, protective eyewear and several pairs of gloves. The bacteria in the colon, which causes an acute odour to the diarrhoea, made providing care for her unpleasant. Beth, one of Betsy's daughters, comes in during the afternoons to bring fresh laundry, and spends time "sitting and chatting with Mom." They mostly end up holding hands, sitting silently together looking out of the window. Sometimes they even watch a children's animation film—Betsy's new found fascination. Her daughter sprays an aerosol to neutralize the pungency, and reminds me ever so politely again to dispose of Betsy's bright red biohazard garbage bags on a regular basis.

As I enter her room, I notice that Betsy is awake. I bring a cup of water to her mouth and she takes a satisfying slurp from the straw. I re-position the hand-woven blanket so that it covers her left leg, which is straying outside the bed's confines. Her feet, sticking out of her compression socks, are noticeably dry; I make a mental note to apply some lotion to her later. Heading further into her room, I make my way to the closet and pick something versatile for Betsy to wear, something that will keep her warm (from the draft in the corridors), but won't make her sweaty, a fine balance indeed.

An hour later, I decide to get Betsy up for the day. It's about 9:00 a.m., which is an hour earlier than the time most caregivers finally get to her. She is already eyeing me from her the bed when I enter.

"Well, good morning"

Betsy replies, "Hi."

"So, today is shower day. Are we ready?"

A one word reply, "What?"

"Yes, you haven't had one in a week."

"Well I don't need one. I can shower myself."

“Well, lets just change you first.”

“Change me?!...Change me from what to what?”

“Betsy, you know the drill. You had a BM; we have to change you.”

She cleverly responds, “I don’t think I need to be changed. I am not a child.”

Moments later, after I wipe her and clean her sufficiently with a few sprays of an unscented cleanser, I pull the room chord to alert the other caregivers that I need help transferring Betsy to the toilet. Since Betsy cannot bend her legs, and is stiff as a rock from the waist down, fastening the harness around her while still half dressed, and getting her knees to form even the most obtuse angle causes her a tremendous amount of pain. Every morning, her mood sours when I bring the Hoyer closer to her bed. Betsy hollers. A fellow caregiver, a woman in her late thirties from Cameroon, comes in to help me with finishing the transfer and the impending shower.

“Why that look Betsy?” Before she could reply, I insert, “It’s your shower day. You are due for one.” Betsy mumbles something sotto voce. I look at her and smile; she is angry and sticks her tongue out at me. And so, what do I do? I also stick my tongue out at her, and one of the widest grins appears on her face.

For the rest of the day, Betsy manoeuvres herself in the wheelchair, with her left foot on the ground, and the other foot suspended in a slightly elevated foot-pedal. She keeps an eye on ‘her’ cat, and positions herself in the middle of the hallway, or in front of the elevator so as to be in the way of others. Sometimes, the caregivers try to wheel her back to her room. When they reach the entrance to her room, she says, “What’s this? There’s no one here.” She then puts her left foot down, and physically resists the wheelchair from going any further into the room. Oftentimes, she would push her Tacoma Pastures issued call button necklace. When I approach her in these situations with a pen in hand to reset the call button, I often ask, without even thinking or waiting for a real response, “Are you alright?” Then, no reply. Betsy was not bored, and I did not think that she wanted to ‘liberate’ herself either. She just knew that this was not a place she wanted to be.

Betsy and I were subject to Tacoma Pastures's care plan, which was tailored to her wishes and 'needs.' We were also subject to the tyranny of time. I had twenty-five minutes to get Betsy out of bed in the morning, cleaned, changed, dressed, and presentable for the dining room. Our routine was linked up with other care plans and integrated into a larger system of monitoring and control. Not only was there a checklist that each caregiver had to hand in by the middle of their shift to the head nurse, but after taking care of each resident, the caregiver had to log on to a computer and chart what they did and saw according to a set survey. Betsy and I were inscribed in an organizational practice with rules and objectives, yet we found ways to express our shared grievances. Short of throwing her faeces at us, Betsy was an expert at resistance. She would rephrase our questions in new contexts, and would oftentimes hold firm to her wheelchair when she did not want to go somewhere or do something. Her physical strength was still intact and this allowed her to manage her space with stubbornness and pride. Betsy would often stick her tongue out at me, and I would do the same to her. She would laugh, and then with more persuasion and jokes, I would be able to convince her to allow me to give her a shower. My joking with her was not intended as a taunt, but rather as a way of conveying to her that I felt her frustration. My intuition tells me that she knew this, because she allowed me to help her with things that she never allowed other caregivers to do. Part of this joking and resistance on my part wasn't so much about gaining Betsy's cooperation, but was rather an instance of self-demeaning. I often found (with much disappointment and surprise) that I was impatient, frustrated and overly physical with my residents. I was disgusted at myself, and when I was confronted with being just a human, another regular caregiver, the abject nature of this led me to champion Betsy's rebellions. Not only did I sympathize with Betsy, but I also lived vicariously through her, especially when she told off the management with great vigour and conviction.

Conclusion

It is clear that the residents of Tacoma Pastures are final receivers of care; they will never care for someone else in the same physically intense and arduous way. And while there is no intrinsic meaning to old age, there can be meaning in ageing. The interactions between formal caregivers and residents reveal that meaning is re-made everyday, and that this meaning is nothing more or less than what it means to live as a social person. We must not stop here, though. Why is it that taking care of an elder person carries with it so much resistance, internal struggle and ambivalence? Isn't it a privilege to escort someone to the end of life (and possibly beyond)? Family members begin grieving and preparing themselves for loss when their loved ones move into a long-term care facility. A lament takes hold during these transitions. Caregivers are looked upon as grim reapers, making the process of moving, downsizing and ageing an uneasy ending (Shield 1988). It seems that if we are to think more about and alter what motivates and constitutes our care, we must unsettle the narratives we tell (about) ourselves.

Chapter 6: The Exigency of Care: Caught up in the Transitions of a CCRC

This chapter explores the transitions residents make in Tacoma Pastures. When I first began my fieldwork working as a caregiver, I thought I would be assigned to the more independent wing of Tacoma Pastures before graduating on to what I assumed was the more challenging work—that is caring for residents with Alzheimer’s Disease. Contrary to what I initially thought, the opposite occurred: I was actually assigned to the dementia unit first. I came to learn that because independent residents were capable of requesting more things like additional food and drinks, in addition to instructing caregivers on how they want their food delivered and their beds made, working shifts in the independent sections were faster paced and hectic. Caregivers in these sections had to respond to a large number of call buttons being pushed by residents almost every ten minutes, in addition to their scheduled daily tasks. In contrast, dementia residents pushed their buttons seldom.

Different levels of care are assigned to residents, and associated with varying physical locations within the CCRC complex. Each level is associated with certain services, tasks and responsibilities. Care Level 1 stipulates that the caregiver must give verbal reminders to their residents about bathing, dressing, eating, and ‘self-managed continence programs.’ Care Level 2, however, requires the caregiver to physically assist with dressing, grooming and bathing. Of course, different levels come with different price tags, and this is one of the reasons people do not want to transition to another floor or wing.

Some researchers working within the field of nursing and social work have looked into how a resident’s network might change as a result of relocations within the CCRC. They have also studied whether or not residents in a CCRC are more social, and capable of maintaining various hobbies and occupations (Shippee 2009). What has not yet been explored, is what actually changes in this continuum, and what these changes for the resident actually reveal about the CCRC as an institution; how aging, personhood and care are interpreted; and how these interpretations are taken up or resisted by the residents. There are competing exigencies between the experience of aging and the practice of caregiving that are constantly in negotiation. Unlike the sunrise/sunset

model of human development, which still dominates our thinking regarding the life course, I find myself now forming an inquiry in an indeterminate situation. Rabinow's recent reflections on Dewey are worthwhile to mention (Rabinow 2008). Rabinow argues that although Dewey's philosophical project was never fully historicized, Dewey's understanding of the nature of inquiry is something modern day anthropologists could resurrect, and seek to engage with and modify. As an initial entry point, one must recognize that "Inquiry is not an empiricism in the sense of discovering what is out there as if it were transparent and passive, simply waiting to be presented" (Rabinow 2008, 8). Rather inquiry is experimental in its form giving. Rabinow goes on to say, "[...] the interest of an experiment is its ability not to represent a pre-existing situation nor to construct an entirely new one but rather reiterated and controlled adjustment" (Rabinow 2008, 9). It is to Rabinow's credit that he has articulated things in such a way and that anthropology is a kind of experiment whereby the ethnographer is embedded in a situation, the conditions of which are existential. It is with this mind-set, that I am attempting to explore what transitions and care might mean.

Therefore, the upshot is that CCRCs are designed particularly with the ageing process in mind, as a kind of problematic process. In conjunction with this, the CCRC can be viewed as a way in which the later stages of the life cycle are given over to material and spatio-temporal administrative treatments. Shippee suggests that, "[...] research on transitions between levels of care in CCRCs is almost nonexistent; yet, these transitions represent a fundamental microcosm of the aging process in general" (Shippee 2009, 425). This process is consolidated, segregated, and displayed within the confines of the CCRC. The question then becomes, what do we track? Who or what has agency? Do we expand on Annmarie Mol's work (Mol 2002) and suggest that ageing, like disease, is produced at multiple sites across the praxiologies of a therapeutic landscape? In other words, is care articulated differently across various kinds of bodily, medical and administrative transitions? How should we follow the person through the various changes that seem to be determined by organizational norms and regulations of risk, control and care (Mol 2008)? If we do this, what data should be collected? How do persons become and un-become in such a place?

Betty

When I first met Betty, she was sitting in the common room on a green upholstered Victorian chair, directly outside the entrance to the formal dining room. Two other residents were busy admiring the new flat screen TV, but Betty was preoccupied. Her purse was open, and she was frowning with worry. I had seen Betty before, but since her room was on the ground floor by the entrance to Tacoma Pastures, she was in a section I had not yet worked in. Like Betty, most of the residents on the ground floor were categorized as semi-independent. She moved to Tacoma Pastures about ten months ago with her older husband. On this particular day, Betty was distressed. She kept rummaging through her purse, hoping to find something.

I took a seat across from her, and decided to strike up a light conversation. The time was about 11:00 a.m., and it was my fifteen-minute break before the residents' lunch hour. I engaged her: "Hi, how are you?" She replied "Terrible." She continued, "Well, I can't find my husband's phone number. I want to call him and let him know that we have to move." I asked why and where to? She answered, "To the fifth floor. I don't know why I have to move. They didn't even consult me! I don't want to leave. I like it here."

Unbeknownst to me, Betty's husband had passed away more than six months before. She was convinced that he was still alive, and that all these moves and decisions were being made behind her back without her consultation. A few days later, I approached another caregiver, who happened to work on the first floor, and asked her about Betty. She said, "Oh Betty? She has to move because her dementia is getting worse." I probed, "Really? Well she seems quite with it." During my first encounter with Betty, she talked vividly about her upbringing in a white middle class suburb of Detroit, and how she could remember her neighbourhood, and her close friends who she thought still lived in Royal Oak. My colleague told me, "Be careful. She is great at convincing you that nothing is wrong with her."

Two weeks passed, and now I found her in my section on the third floor. Betty had made the move. I was quite puzzled by the situation, and asked the social services officer, a full time employee of Tacoma Pastures, why Betty was not consulted. The officer told me that a joint decision was made by the Tacoma Pastures community, and Betty's own son

and daughter. Furthermore, the officer assured me that Betty was present at the meeting.

There was never a move to the fifth floor of assisted living. Betty moved to my section, officially called 'Memory Care.' On the third floor, there are three corridors, and all of them are electronically locked. You also need a four-digit code to access the elevator from the third floor. Betty was given a new care plan, which had to be coordinated with other residents' care plans. She was now under full scrutiny, and embedded within a different system of care with its own rhythms and priorities. It was determined that she should take at least two showers per week: Tuesday and Thursday mornings after breakfast. On Tuesdays, as part of the level of care and service package provided to dementia residents, in addition to 'reminding' Betty to take her shower, I had to take her vital signs and call the nurse to conduct a skin check just before she got into the shower or shortly thereafter. Because she was considered still relatively independent, Betty didn't require me to toilet her, brush her teeth, and get her dressed in the morning. Therefore, I spent more time assisting the other nine residents who fell under my care. As a result, I checked up on Betty much later in the morning. As the weeks passed, Betty started sleeping in more often. This posed a problem for the kitchen staff who wanted to finish serving breakfast by 9:00 a.m., because they wanted to take their breaks before cleaning up and setting up for lunch.

Moving to Memory Care was something that Betty never fully accepted. Unlike other residents in the Shimmering Waters community (each wing of the third floor was named after a local river), Betty always carried her purse with her, as if she were going somewhere. Because Shimmering Waters was designated a 'secure neighbourhood', caregivers had to cover their hands when inputting the security codes to come in and out of the various corridors, like someone at a cash machine. Even though Betty said it was ridiculous that she needed an escort now to go downstairs and to take a stroll through the common area, she did not resist much. I say this, because another resident in Shimmering Waters would often rush to the door after lunch with his walker and look to sneak out. On several occasions, Gary would bang on the door, and plead with one of the caregivers that he had won a few dollars from bingo, and needed to go to the small shop downstairs. Caregivers would tell him that he needed to wait for an escort, and that it was best if he could sit back down in the gathering room opposite the dining room.

Sometimes the caregivers were successful in redirecting him; they would put on his favourite medley of sing-along songs and this would lure him back into his chair. Other times, however, he grew agitated and would block the entrance/exit by sitting on his walker right in front of the door—so that no one could come in or go out. Whenever this happened, caregivers would call him on his mobile and pretend that they were a friend or his daughter on the other line. Caregivers would say, “Hey Gary. You got a call”, and on the other line another caregiver pretended to be someone he knew. Such creative lying techniques, however useful they may be in redirecting such unwanted behaviours, were seen as an annoyance, and an additional task that caregivers had to reluctantly take on.

Luckily for Betty, in the eyes of Tacoma Pastures (i.e. the nurses who work alongside and rely on the caregivers’ observations and daily assessments), she didn’t display any ‘behavioural problems.’ As a result, she was saved from having to take Aricept and other anti-paranoia medication. Not only were the caregivers constantly evaluating Betty, but also her own son and daughter who lived nearby also checked up on her. Betty’s family had put up a clipboard, detailing who had come to visit, the time of visit, and the status of her personal laundry.

A few months had passed since Betty’s move to the third floor, and she was still carrying her purse with her everywhere she went, even if she was going to lunch in the dining room—which was just a few feet away. This was unique because no other woman in Memory Care was clinging on to her purse anymore. Additionally, Betty’s son and daughter decided that she couldn’t have a telephone line anymore, because she had racked up quite a large phone bill. I discovered this for myself, when I came to her room and saw that she had procured a telephone book, and started going down the list calling every David she could find. Unsurprisingly, her husband’s name was David. When her phone privileges were stripped away, she developed a new ‘behaviour.’ She complained constantly that she couldn’t find her room key or that her room key didn’t work. Caregivers who were less than patient did not take to this very well. I knew that the key was in her purse, and all that she needed was old-fashioned TLC—at least that’s what I told myself.

On the first floor, caregivers change bed sheets, and take vitals only when residents are sick or slip accidentally. Med techs are the ones that engage the most with these residents,

because they have to pass out medication (e.g. after a meal for some residents or first thing in the morning for others). First floor residents treat their rooms as apartments; they are free to come and go as they wish. Many of them have cars, but no one in the CCRC has their own kitchen. At first, Betty moved to Tacoma Pastures in order to be with her husband, who subsequently fell ill and died rather abruptly. After his death, Betty couldn't stay in her room on the first floor. She spent the majority of her time wandering the common room and the public entrance space. Betty's insistence that her husband was still alive, and that she had to locate him, caused the CCRC management concern. Her own adult children, who I often saw come and go rather swiftly, agreed to have their mother move into Memory Care. It was an embarrassing situation for them, and this became clear to me in the way her son and daughter came and went abruptly—usually on Saturday mornings. They came to change her personal laundry, but not once did I witness them really engaging with her and/or her fellow residents. When I approached her son in the hallway, he said that one of the full-time caregivers was just great, and that Betty was in good hands.

In Tacoma Pastures, no one ever explicitly said that Betty needed to move because she required more care. Instead, several nurses and caregivers stated that Betty was a risk to herself; she could wander off at any time. Before Betty moved, she was on the first floor, but she did not interact with other residents. After moving to Memory Care, Betty had to share a living space with others. Being confined in the locked unit, and embedded in the system of care meant that Betty had transitioned. Yet, transitioning from what to what was still a question that Betty did not figure out, and this proved to be rather alienating for her, especially since she was always ready, with purse in hand, to seek answers.

Mary

As a part time caregiver, I worked on the third (Memory Care) and fourth (Assisted Living) floors. Mary and Dennis Johnston moved into my section on the fourth floor, and fell under my care about three months after I had been offered a position as a caregiver. Before this, I was a volunteer and worked with the recreation department, visiting residents throughout Tacoma Pastures. As a volunteer, I devoted most of my time to the CHR section of the CCRC campus, visiting people in order to talk to them and keep them

company. The CHR is licensed differently, because unlike the rest of Tacoma Pastures, it is a SNF. Caregivers undergo more training and earn a slightly higher wage (I made roughly \$7.25/hr. while caregivers in CHR made about \$11.45/hr.). Mary and Dennis moved to Tacoma Pastures because Dennis was facing some physical health problems (it was never made clear to me what he actually suffered from). Caregivers are not officially privy to the kinds of medication and ailments their residents face, unless this information directly impacts the way caregivers have to assist them in their daily activities. If someone breaks their hip, and returns from surgery, caregivers obviously have to know about this and adjust the way they help them shower and transfer in and out of bed. We also learned from the care plans that we consulted and checked off daily who had Parkinson's; this information affected the number of caregivers required to assist residents with unstable gaits to move about, or to transfer them in and out of chairs and beds. Dennis, however, was still walking and did not require a walker, although many of the caregivers felt that he needed one. There was nothing out of the ordinary in Dennis's care plan. The same could be said for Mary. All in all, some allergies were noted along with a schedule of linen changes and dietary requirements.

My focus here is on Mary, and her many transitions in and out of Tacoma Pastures. Dennis's health was rapidly declining, and I overheard from the nurses and caregivers that his liver was failing. This could have explained why he was going into the city so often to visit the hospital. Dialysis was not something new to him, but for one reason or another this was not an option this time. After about a month, and taking note of Mary's increasing insomnia, it became clear to me that Dennis was not going to make it. Dennis moved to the hospital, and was placed promptly into the hospice unit.

The day after Dennis died, Mary's son and one of her daughters who both lived not more than 5 miles away came to visit her. They tried to take Mary back to her daughter's house. Mary eventually went, but after dinner she refused to spend the night. Neither did she have the stomach to go to lunch the next day with Dennis's brother who flew in from Chicago. For the next couple of days, family members from Chicago and Iowa flew in to visit and attend the funeral. I entered Mary's room at 9:00 a.m. two days before the funeral to deliver the newspaper, and to bring her usual banana and black coffee. She was sitting on the couch. Everyone was holding hands across their laps in a communal fashion with Mary in the centre of the couch. Her children and grandchildren were

clearly saddened by the loss. When I stepped outside, one of her daughters followed me out and said, “I really worry about Mom. This is a huge blow to her.”

Mary and I had developed a friendly relationship over the course of my caregiving. I spent an hour after my shift concluded in the few weeks leading up to Dennis’s death having coffee with her. During our coffee sessions, I didn’t attempt to interview her, nor did I feel the desire to. I simply wanted to just be there—for her. It was probably a nice distraction for her to talk to me about Chicago, and growing up in a large Catholic family. She told me that she was so happy that the four grandchildren who came got on so well with each other. She stressed to me (more than once) that family was important. During one particular afternoon session after Dennis’s death, Mary tried to hold back her tears. She squinted as she usually did through her left eye, but this time her right eye betrayed her and she started tearing up.

I was invited to Dennis’s funeral and attended the Saturday morning service. Thankfully, it was my weekend off. There were about 200 people in attendance. Dennis had retired many years earlier from a successful career in malpractice insurance. Mary was not in the front row of the church, although she was clearly in view and surrounded by her children and grandchildren who took up the first few rows. Each of the four grandsons was called to the podium to say some words of reflection and praise. They were each wearing one of Dennis’s old ties. Even though I was in the back, my focus was on Mary. She did not cry once during the funeral, but I could tell that she was still in a state of shock. She wasn’t sleeping or eating properly, and this intensified her overall pale complexion. One of Dennis’s cousins came up to the front of the church, and told the crowd that their entire family has been taking a one-week vacation together every year consecutively for forty years. We were also told that all of Dennis’s daughters were still married; no one had divorced. We heard a little bit about Dennis’s service in the Marine Corps, and that Dennis had made up his mind early on that “conflict was over-rated.” The homily delivered by their family priest recounted the story of a girl who upon learning that her grandfather enjoyed collecting hourglasses, decided to give him for his birthday one year a box of sand. Afterwards, we were dismissed by a Catholic hymn named the Summons, taken from the traditional Scottish tune Kelvin Grove. At the end of the service, Mary was by herself, slowly collecting her things in order to make her way to the front of the church. I wanted to hug her, but felt awkward. I walked up to her and

said, slightly solemnly: “Hi.” She looked at me with a tired smile and said, “Thank you for coming.”

In the weeks that followed, Mary did not come out to the dining room for lunch or dinner. Her son and daughter who lived nearby came at least once a day to sit with her, and tried to take her out. Mary kindly refused. I continued my caregiving tasks, which amounted to refreshing her drinking water, taking out her trash, and bringing her some food from the kitchen. Things for Mary, however, did not look up. She had slipped and fallen outside on the way to her daughter’s one afternoon. Mary broke her hip, and after the surgery, she was taken to the CHR. At the CHR, she shared a hospital-like room with another person. Not more than a few weeks after the surgery, the doctor discovered that her blood sugar levels were very unstable and fluctuating quite dramatically. While Mary was at the CHR, her care plan from the fourth floor did not follow her. Caregivers at the CHR knew nothing about her likes and dislikes, her dietary needs and even her past medications. She was completely new to them, even though she was living not more than a few yards away in another section of Tacoma Pastures. Since the CHR had a different staff and set of regulations, my previous caregiving had no place in CHR. One day, I ventured up the fourth floor to seek a new thermometer from a fellow caregiver, when I noticed that there were many papers stuffed under Mary’s door. I took out the universal room key attached to my beeper-device and entered her room. When I walked in, I discovered that she had about two weeks worth of newspapers and mail sitting right next to her dresser by the front door. I took these to her, and made it a habit to deliver her the paper. But as time passed, I noticed that no matter how late in the morning I arrived, she was asleep, and all I could hear was the gurgling sound of her buzzing oxygen concentrator.

Mary eventually moved back to the fourth floor from the CHR. It costs much more to stay in a SNF like the CHR than it does to stay in the assisted living units or even Memory Care. Mary was getting weaker, and needed a cane to move about. She was also signed up to have someone from the physical therapy department take her three times a week to the gym downstairs to begin her rehab sessions. This service came at an extra cost. Mary went to a few of these, but soon lost ambition. I spoke to her about trying her best to rehab and to continue fighting on. She recognized what I was saying, but told me, “I don’t have the will anymore.” Soon enough, Mary moved out of Tacoma Pastures quietly

in the course of one day, and checked into the same hospice her husband was in. She was next door to the room where Dennis spent his final days. One day after work, I decided to drive into the city to see her. Her daughter from Chicago and her two college-aged children were also present. Mary was happy to see me, and offered me a cookie. There was not much I could say. She was in hospice now, and comfort was all that anyone could provide her. A few days later Mary died at the age of 86, and the comments posted on her online obituary read:

“My children will always think of her as grandma Johnston even though they are not related to her. She was the kindest, sweetest most caring woman I have ever met. She and Dennis were the most adorable couple and they were the perfect example of a great marriage.”

Mary’s transitions were motivated first by her husband, and then by a series of incidents. What became clear was that relocating to new sections did not help her in anyway. The biggest change in her life was the loss of her husband. There was no level of care or floor at Tacoma Pastures able to cater to her grief. It is unfair to say that she was a victim of the institution, or that she fell through the cracks of the imagined continuum. Moving to CHR, and then back into her room after surgery was certainly tiring and stressful. Mary had lost the will to live, and decided that there was only one transition she was in control of, which was probably shrouded from her God in an interior world.

Katherine Froggatt says that: “There is much uncertainty inherent in the boundary between life and death for many residents in nursing homes. The relationship between life and death for these residents is less about the sequestration of dying people from living people, but rather the creation of transitional states between these two polarities” (Froggatt 2001, 319). At Tacoma Pastures, transitional states between the living and dying were demarcated in subtle ways. While the stigma of moving to the skilled nursing part of Tacoma Pastures is something that is widely acknowledged by the residents upon talking with them, but rarely articulated, preparations for death are more elusive. A Tacoma Pastures caregiver who used to work at a Catholic-run nursing home said that death was not something that was taboo. It was talked about and “hard-wired into the care plan.” Some of the residents who fall increasingly ill and look as if they are not going to live for much longer are often transferred by their family members out of

Tacoma Pastures and into hospice. For others who happen to stay at Tacoma Pastures for their last days, a 'comfort cart' is given to family members and visitors, consisting of a teacart with cookies, hot drinks, a tissue box, aromatic candles, and a small portable stereo with a selection of relaxation CDs.

Immediately after a resident dies, 'post mortem care' at Tacoma Pastures ensues. This involves a series of tasks that have to be completed. Firstly, two nurses must see the resident and make an official death pronouncement, as a kind of speech act. Secondly, medical equipment such as an oxygen concentrator must be unplugged and removed. Caregivers have to bathe the body and cover up any wounds with a Band-Aid. After dressing the body in a new set of clothes taken from the resident's closet, the body has to be laid on the bed, making sure that the eyes are closed, and that dentures are inserted if applicable. A pillow must also be placed under the head and a rolled towel must be placed under the chin to keep the mouth closed. All of this is done so that when the mortician arrives, the body is then ready to be placed into a black bag. The final thing for the caregiver to do is to place the Tacoma Pastures 'Memory Quilt' over the body so that the black bag does not show. Once the body is placed into the hearse, the caregiver takes the memory quilt away and turns it into the laundry department to be washed, folded, and returned to the nurse's station. A framed note with the deceased person's name is placed next to an electric candle in the public space just outside the resident's room.

The Tacoma Pastures's memory quilt is not really a patchwork quilt, but a striped coloured blanket of greens, blues and yellows purchased at the local department store. Some people at Tacoma Pastures assert that the memory quilt is an old fashioned and hand made quilt, while others maintain that it is just a white blanket stitched with the word Tacoma Pastures. When I first learned about the memory quilt, I asked one the med techs about it. She wasn't sure what the quilt looked like but explained that it was used as a courtesy. In her words: "So that when you drag the black bag out, it is unsightly for the residents to be seeing bodies hauled away in day time." A licensed practical nurse (LPN) who works with the head nurse said to me that: "The memory quilt was a way to say good bye for transition. I suppose it is tradition too. It is used to keep comfort so that even when they are taken away, they are still transitioned in comfort and in Tacoma Pastures's care."

Harry, the former 'Culture Director' of Tacoma Pastures, told me that the quilt is used when someone passes away to cover them while transferring them out to the ambulance. He said that the memory quilt was an idea that he and others got while touring other facilities in Indiana. He said it was good to have, so that in place of the 'barbaric black bag' we are showing our respect for the dead. I told him what people at Tacoma Pastures said regarding the reason and use of the quilt. Harry was a bit surprised by how the meaning of the quilt changed over time. He said that in his new job at a Catholic long-term care facility, when someone dies the roommate is given the first chance to say goodbye. Before any thing happens, the staff and others come in and say their prayers. He also mentioned that the person is escorted through the front door, and not the back, and that people sing songs while the body is being placed and transferred into ambulance. Harry made it an issue to say that: "Most people will arrive in a nursing home face up on a gurney [trolley], and their first impression of their new place of residence will be looking up. When they leave, they will also be face up on that same gurney."

Conclusion

Barbara Myerhoff famously remarked that ageing is a career (Myerhoff and Simic 1978, 231). Its vicissitudes are ungrateful; and transitions are inevitable. In the CCRC, transitions are marketed as personalized and tailored. The staff pay lip service to the charge that they are helping residents strive to maintain a sense of dignity, familiarity and home for as long as possible. In fact, one of the Directors of Operations at Tacoma Pastures kept on saying to us during our weekly meetings that, "We have to be committed to the 'journey of life', and that care allows us to find a way home." One of the CCRC's guiding principles is to reduce the amount of stress for the elderly by providing 'on site care.' What I came to discover was that such transitions were never smooth, straightforward or even predictable. Moving into Memory Care carries with it social marginalization and stigma; it is a taboo subject among residents at Tacoma Pastures. Former neighbours rarely visit residents who move into these sections. On the face of most residents, a blank wisdom of acquiescence leaves one never quite totally resigned.

Looking out into the setting sun from the cavern, what are left are the remainders of the day, and the annoyance of ageing so close with others who are also ageing.

Betty's transitions were taken for granted by everyone around her. But from Betty's perspective, she could never accept them. She was constantly grasping for answers, asking questions and seeking out better explanations. For Mary, moving in and out of the various care units in Tacoma Pastures was a response to her deteriorating physiology. Yet despite these transitions, Mary was looking for a way out of the continuing cycle of blood tests and rehab sessions. She had a choice, and her choice was a will against the preservation of life. Mary's resistance could be construed by some as a failure, but she took an active decision in leaping beyond the structure of care to end her life peacefully, not with a sudden pull of the plug, but with a sliding diminishment.

In Tacoma Pastures, residents may not have much longer to live. Yet, even so they have a lot of time on their hands. They spend hours sitting silently in common areas, waiting to eat their uneventful meals of sustenance. For some, time is neatly managed; and residents in Memory Care and Assisted Living serve the clocks of their institutional settings. They have to get up, even if they don't want to. They are fed before 9:00 a.m., and some are made to wear adult protective bibs at the eating table. Furthermore, lunch is served between 11:30 a.m. and 12:30 p.m.; there is no departure from this schedule. Snacks may be permitted, but there is no deviation from the regimen. In the CCRC, residents are not conscious slaves to the clock, but as an outcome of various disciplining practices, they are made more aware of their bodies, but most of the time they are too tired to resist such imaginings. The CCRC attempts to model how people age, and in doing so it aligns the various articulations of ageing with manufactured levels of care.

Chapter 7: When Frost Happens in the Garden: Person-Centred Care and the Eden Alternative

This chapter offers an inside look at how corporate ideas of ‘culture’ and ‘culture change’ affect an organisation in unintended ways. Lustbader and Williams claim that the first usage of the term ‘culture change’ in the long-term care context stems from a gathering initiated by the National Citizens’ Coalition for Nursing Home Reform in 1997 (Lustbader and Williams 2000, 645). During that gathering, providers of long-term care who were against the traditional nursing home model of care began looking for a new ways to talk about new practices and approaches to caregiving. It was during this informal gathering that the participants began to formulate a conception of *culture* of and in the nursing home as, “[...] expressed in its traditions, style of leadership, social networks, patterns of interaction, relations with the outer community, degree of connectedness to the natural world, use of language, and ways in which the community celebrates and mourns” (Lustbader 2001, 187). Looking at certain institutional reforms and elder-care practices, couched in terms of a nursing home abolitionist movement and ‘programme’ known as the Eden Alternative, I discuss how Tacoma Pastures deals with transformational discourses that are not always about care or the quality of life for residents at Tacoma Pastures. What follows is a discussion of various regimes of care, and ideologies that are kept always in control.

In an influential essay on organisational ethnography, Rosen discusses the use of ethnographic methods to better understand the nature of control in formal organisations (Rosen 1991). Rosen says that control is often seen from the management’s perspective, and thus given over to reifying the objectivity of the management’s ‘scientific’ perspective and reproducing the structures of authority. He sees control as being taken for granted too often in the context of formal organisations, where the emphasis is on control over the labour process. Rosen describes this popular idea of control as a two-sided relationship, where labour power is exchanged for wages. Yet Rosen claims that oftentimes there involves more than just an instrumental exchange of work for money. According to him: “[Control] involves an exchange of such commodities of the human fabric as loyalty, self-definition, love, sacrifice, and so on” (Rosen 1991, 9). What is complicated in the context of Tacoma Pastures is that this

control, over the bodies and actions of residents and their caregivers is couched in terms of quality care and person-centred care that resists any criticisms or deconstruction. Ryvicker shows how this control over the use of language and the instantiation of different organisational cultures aimed at discursively serving up issues of autonomy, dignity, and preservation of 'identity' in late life can yield more sinister consequences (Ryvicker 2009). Drawing from two different long-term care facilities, her research shows that caregiving practices vary between two homes in ways that the administrators foster (i.e. control) different types of caregiving relationships. What Ryvicker found was that in contrast to the more sterile and therapeutic-like setting, the more informal and home-like setting infantilised the residents and encouraged an unhealthy passivity. The crux of the problem is that control and care in an organisation such as the CCRC feed off of each other; resorting to structuration is not sufficient for such a moral space charged with power and vulnerability. No one at Tacoma Pastures could be said to own or direct its brand of corporate culture and identity. Even though Tacoma Pastures claimed to be certified in the Eden Alternative, a set of guidelines to redefine care and transform the way elders are thought of and engaged with in long-term care facilities, no one person or office owned or controlled this initiative. As I will show, this was a corporate culture that was never 'internalised,' and perhaps on purpose.

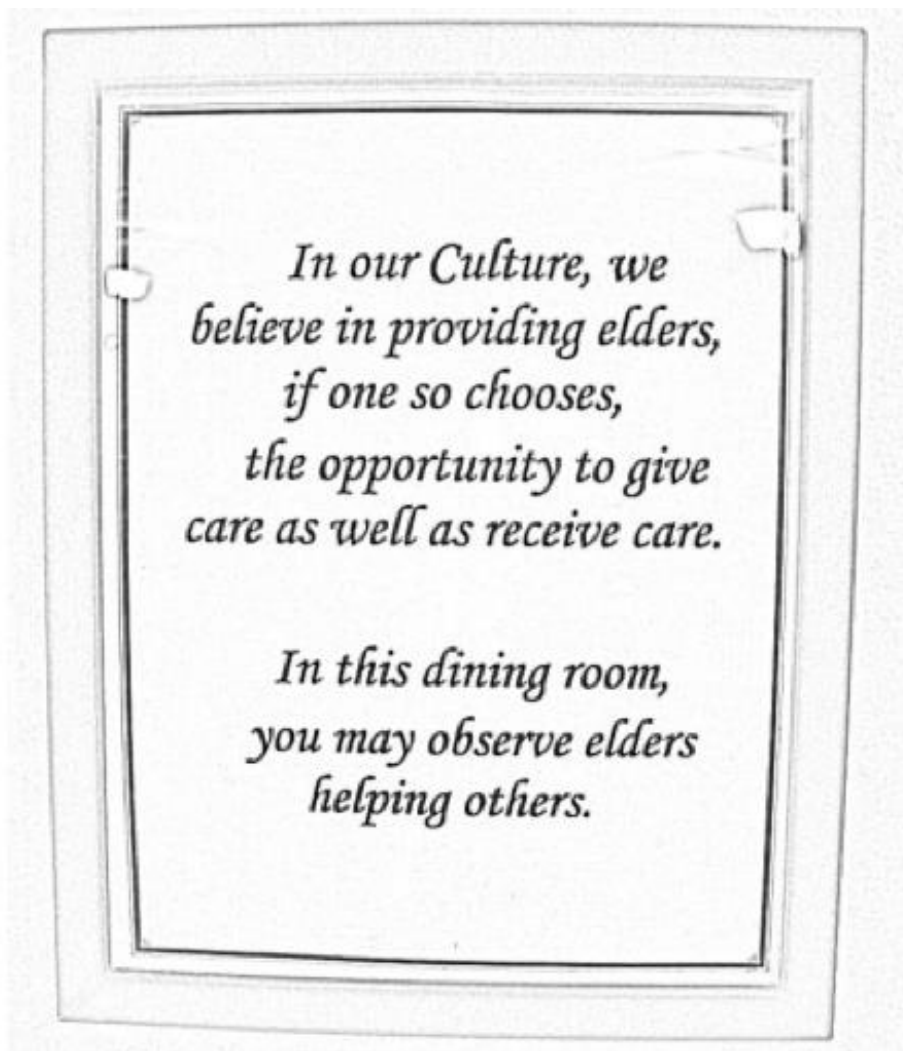
Nursing home reformers - colloquially known as nursing home 'abolitionists' in the US can trace their roots back to the work of Harvard-trained doctor Bill Thomas.²⁶ In the early 1990s, Dr. Thomas and his wife founded the non-profit Eden Alternative culture change model in order to work towards deinstitutionalizing long-term care facilities by alleviating their professed 'three plagues' of ageing: boredom, helplessness and

²⁶ Part of the reform can also trace its roots back to the 1980s with the restraint-free movement. In a New York Times Letter to the Editor published on 02 Dec 2012, the chief executives of LeadingAge and Jewish Home Lifecare wrote: "The restraint-free movement has been under way for more than 20 years, and many care providers have eliminated the use of restraints completely. For years, nursing homes have moved toward creating restraint-free environments that feel more like home, promoting both the safety and quality of life for those in their care [...] Bed rails, while an obvious type of restraint, are but one example; chemical restraints (mood- or behavior-altering drugs) are another. The ultimate goal: restraint-free living for nursing home residents." Letter can be accessed through: <http://www.nytimes.com/2012/12/03/opinion/restraint-free-care-for-nursing-home-residents.html>

loneliness. These plagues soon blossomed into principles, a biblical ten to be precise, and today the international not-for-profit organization has grown in size. According to Brownie, “at least 200 American aged care facilities have adopted the Eden Alternative’, and there are ‘Eden Alternative facilities in the United Kingdom and Ireland; European countries, including Germany, Austria and Switzerland; Scandinavia countries, including Sweden, Denmark, Finland, and Norway; Japan, and other countries” (Brownie 2011). The founders of the Eden Alternative idea describe their mission as being: “Dedicated to transforming care environments into habitats for human beings that promote quality of life for all involved.” It is a powerful tool for inspiring wellbeing for elders and those who collaborate with them as care partners. Furthermore, managers working in long-term care facilities that wish to ‘Edenize’ their institutions are encouraged to: “A) Treat employees appropriately B) Ensure that decision-making is nearest the resident C) Commit to changing the living/working environment and D) Persuade everyone to grow continuously.”

In a nutshell, Eden’s ten principles are aimed at granting elders more decision-making powers by reversing what is perceived as top-down bureaucracy. Lustbader and Williams state that: “Shifting these ‘pyramids of power’ [the bureaucratic and power structures topped by physicians and head nurses] turns out to be the essence of a transformed culture of long-term care. Those who have the most contact with the ill person, the nurse’s aides, must be given a primary voice on the health care team, and the locus of control must be returned to the individual, rather than retained by the institution and its staff” (Lustbader and Williams 2000, 647). Eden is also about creating more human spaces: so that plants, pets, and visits by community children to the CCRC provide, as stated on their website—‘a pathway to make life worth living’. The Eden Alternative promotes both autonomy and dependence, sending potentially mixed signals. On the one hand there is praise for self-reliance and individualism, yet on the other there is a quiet recognition of the need for dependence and interdependence in creating and sustaining social relations in places like Tacoma Pastures. Eden principle four, which is framed in each Tacoma Pastures dining room, says that people are most happy when they receive and offer help (see figure 12). Principle seven also stands out in particular, which states: “Medical treatment should be the servant of genuine human caring, never its master.”

Figure 12 An Eden plaque



At Tacoma Pastures, there are plenty of birdcages (with birds), plants, and motivational posters presenting life as a journey, and a tree—a somewhat obvious yet elusive symbol. I came to Tacoma Pastures shortly after their Culture Director (an official position created at Tacoma Pastures to help the community realize Eden principles) was fired. After he was let go, Tacoma Pastures decided not to fill his position again. Thereafter, no one at Tacoma Pastures took the mission of Eden very seriously. People working in long-term care facilities pay money to attend various Eden workshops in order to become certified and sponsored. Once they do so, they are Eden Ambassadors, and oftentimes are seen by the management as overly proselytizing provocateurs. Harry, the Culture Director, went out of his way to go against the grain of 'business as usual.' For one thing, he never wore scrubs (a protective garment worn by doctors and nurses) and very much

wanted caregivers to abandon wearing them as well. Some people dressed down and joined Harry in extricating the scrubs from their wardrobes. When he left, however, people slowly returned to their scrubs. Even I caved in to the social pressure of wearing scrubs. I soon noticed that wearing the uniform gave me a sense of self-congratulatory professionalism, security and acceptance among my fellow caregivers. I had the looming sense that an elder would listen to me more, or rather allow me to take them to the toilet after a meal, or every two hours, without any refusal or complaint. It was a requirement to take each resident with dementia to the toilet every two hours. There was even a computer program we had to enter in in order to document the tasks we performed, including the type of stool that someone produced or did not.

Fellow caregivers often commented to me that when the Culture Director was still at Tacoma Pastures, things were fun. Caregivers were allowed to eat pizza with the residents, and people generally had a more laid back attitude. Even workers in the kitchen and the hospitality department were able to postpone some of their cleaning chores to hang out with the residents, and they were paid for this time. There was certainly a shortage of caregivers; on average one caregiver was in charge of assisting and caring for twelve people. Because of this and the incessant nature of the task-list system, caregivers did not have time or feel comfortable socialising with their residents. Moreover, there was a 'social defense system' being resurrected, a system eliminating situations that involved the experience of anxiety, guilt, fear, and indecision (Lyth 1960). We are familiar with corporate mission statements about change, innovation, transformation, and customer service. Long-term care facilities use the Eden certification as a marketing scheme to demonstrate to a prospective family member, usually the daughter of an elder, that their 'community' is a friendly and humane place. I could not help but feel that this made people feel less guilty about checking their loved ones into the CCRC. At Tacoma Pastures, especially with Harry gone, the Eden marketing ploy became a set of jokes and empty signifiers.

Eden did leave a few lasting impressions. For one thing, the directors at Tacoma Pastures decided to embark on altering the everyday language. During my first day on the job as a caregiver, I was given a sheet of paper as part of my orientation, entitled: *Culture Change Terminology* (see figure 13). Patients or seniors were now referred to as residents or elders. Other categories were also given a make-over: Facility/building gave

way to community. The main dining room was now the scenic view dining room; a welcoming replaced the traditional 'admission'; tours were 'visits'; and a room or bed was replaced by the preferred 'apartment'. Additionally, sweetie or honey was replaced by people's real names or sir/madam, and passed or passed away was to be used instead of expired. The scheme was simple enough, 'culture change' in the words of an Eden Ambassador: "is about transforming a facility into a home, a patient into a person, and a schedule into a choice." The intentions were certainly well placed.

Figure 13 Culture Change Terminology

OLD Terminology	PREFERRED Terminology
Patient or Seniors	“Resident” or “Elder” or “Rehab Clients”
Facility or building	Community
ALU (Assisted Living)	Independent Plus
Main Lobby	Resident Center Lobby
Main dining room	Scenic View dining room
Frontline staff	Direct care
Nursing home	Center for Health & Rehab or Community
Referring to someone as their disability or diagnosis	Referring to the person by their name
Main Entrance	Resident Center entrance
Admission	Welcoming
Tours	Visits
Hall / wing	River Name (if applicable)
Feeder	Assistant (e.g. Mrs. ___ needs assistance eating.)
Dementia Unit / Locked Unit	River Name
Room or Bed	Apartment
“My” resident	Resident’s name
“Sweetie” / “Honey”	Refer by their name or Sir / Madam
Expired	Passed / Passed Away

Instead of herding old people together into some kind of care factory, Tacoma Pastures wanted to focus on personalized, or rather person-centred care as part of the marketing strategy. Additionally, Tacoma Pastures wanted to make its space more homely and familiar to its residents. The Director of the Resident Center once said to me:

That the elders are the first and the last, we are trying to make Tacoma Pastures a place, a community, and a home for everyone. You can think of it as a home of homes. We are a family, between residents, between the staff and residents, and even the residents and their own family members. They are welcome to come in to Tacoma Pastures and make it their living room.

In another conversation I had with Polly Fernman, Tacoma Pastures’s risk manager and lawyer, the topic of marketing came up. Polly said: “People are confused about who we are and what we do, and the changing nature of aging. We need a better way to explain and market ourselves to the community.” I thought she would launch into a discussion about TV commercials, but she continued in a sermon-like way. She told me that they just had a meeting with the board of directors asking them to be more proactive. Polly said:

They cannot just be a passive board, they need to know what our culture is and provide feedback. We have many volunteers now who serve the board, most of them whose parents had lived here. They are emotionally invested, but they need to understand that we have a culture. We may not have a brand name, but we have lasted and that's our identity.

I asked her what she thought about Eden, and she happily offered that:

We have playgrounds, and outdoor events. There is always fun and laughter. We are welcoming and you can be yourself. It's a combination of who we are and our established linkages with schools and volunteer groups outside Tacoma Pastures. We are even a voting precinct, so anyone can experience Tacoma Pastures. If that's not Eden, then I don't know what we're doing in our sequestered rooms.

The managers and finance directors at Tacoma Pastures were also very aware that people could cash out of their investment at any time, but they wanted people to stay and age there in order to continue receiving their monthly fees. Checking into a CCRC is a kind of life annuity policy, and there is a whole actuarial science around the accounting and calculation of bed replacement rates.

Eden did not interfere with the regimen of toileting, dressing, bathing, feeding, poking, prodding, moving, measuring, and surveilling. Tacoma Pastures's recreation department aligned their activities to some of Eden's principles. For instance, in combating boredom, the recreation department put together daily events. These events included movie showings, one-on-one visits, sing-alongs, making dog food snack mix (which is made from Crispix cereal, peanut butter, marshmallows, and chocolate chips), bingo, having people sit together and bounce a balloon around the circle, and even bringing local school children to whisk bubbles in a plastic bowl of washing up liquid with the elders.

One of the other Eden principles, however, was also being simultaneously neglected, namely principle 6: Meaningless activity corrodes the human spirit. This principle is grounded in the assertion that the opportunity to do things we find meaningful is essential to human health. When there were no scheduled recreation events, fieldtrips to

the local shopping mall or garden, people spent most of their time wheeling back and forth, circling around common spaces in front of the elevator, sleeping in their wheelchairs, and just plain waiting. There were less appealing options. Tacoma Pastures's recreational calendar of 'social' events and activities were always attended by the same handful of people. Bingo without any prizes, three people doing children's crosswords while the others sleep, listening to obscure folk songs in a group circle, making pretzels and dozing off to TV infomercials were the usual activities. The sheer triviality of keeping someone occupied was a far cry from what principle 6 had in mind, and what Sudoku players often aim for: Stress-relieving mental stimulation. Part of the reason why Tacoma Pastures could not organise better events is their limited recreation funds. Instead of seeing the residents as being bored and tired, another explanation might do. Hazan speaks of the present-bound society as a follow-up to his study of a day-care centre for elderly Jewish Londoners. Because the members of the centre wanted to enact a space of egalitarianism in order to make care and care receiving non-hierarchical and fair, previous career roles and socio-economic positions were never brought up. For Hazan: "This indicates a crucial transformation in the organisation of events and hence in the patterning of time as a static construction rather than as a linear progression [...]. Thus, games such as chess and cards were devoid of their competitive nature because they were regarded as 'teaching situations' [...] Daily activities such as dancing and singing recurred cyclically with very little novelty of innovation" (Hazan 1990, 187). Similarly, but driven by different concerns, the nature of events and activities sought to flatten time, or rather to sustain synchronic time. The present-bound need for keeping things unchanged had to do with the fact that change was rarely welcomed. No news was good news, and the recreation staff particularly made a point of entertaining, but not educating, and certainly not humanising.

After Harry left, the term Eden became an adjective. People referred to certain acts of caregiving or attitudes as either being Eden or not. For example, when I took my own time after a work shift had ended to sit with an older woman in her room just to chat, a fellow caregiver said to me, 'that's very kind of you, very Eden'. Caregivers also attended mandatory bi-weekly staff meetings in order to receive announcements, and to discuss issues with the management about the work schedule, or the implementation of new lifting devices. During these meetings, they would often remark to each other after

hearing the director go on about creating a human habitat, 'I was always Eden. Even ten years ago before all this shit, I was Eden before Eden. I just don't understand all these new pillars. They are stupid'. In fact, Tacoma Pastures initiated its own interpretation of Eden; one employee suggested it was just tailoring Eden to fit the Tacoma Pastures community. Instead of expounding on the ten Eden principles, which could still be found framed on the walls in various public spaces and staff lunch rooms, Tacoma Pastures set out a new set of corporate culture taglines. The mission statement was still 'Dedicated to the Journey of Life', but now it was buttressed by a set of ideas comprising the following pillars: Human Habitat, Education, Fundraising, Events, Clinical Services, and Customer Services.

The people at Eden have come to realize just how hard it is to implement their sense of change. Because of the business need to remain lucrative, the Eden Alternative requires its long-term care participants to re-certify every three years. Re-certification is not a lengthy process, but it does require a new application. The submission package consists of indicating the number and nature of events and activities that have been put on by the long-term care facility. The application also comprises of resident surveys that are actually filled in side by side with a caregiver on the computer, and other fundraising information. There is also a form, requiring such data as: caregiver drop-out rates, evidence of team scheduling, pertinent training sessions attended, if and how care plans have addressed the three plagues of ageing, and even marking down whether or not the manager is present in the dining room during meals. Eden has not been scripted into the care plans, which are compartmentalized into sections denoting: bathing times and special needs, vision and hearing abilities, mobility and transfer requirements (for example whether or not the use of a mechanical lift is needed or whether two people are needed to help move someone), degrees of incontinence, allergies, and dressing and grooming habits.

There is a division of labour at Tacoma Pastures, med techs primarily hand out medicine, caregivers do all the bed and body work, while recreation assistants organize and entertain residents with a calendar of 'fun stuff'. But there is something odd going on. Recreation is blocked off as a time for fun, but not for self-expression. For example, residents are evaluated even during their sing-alongs by the recreation assistants. When someone appears to be anti-social, i.e. meaning that they do not want to participate, or

are not interested in making dog food snack mix, this information is jotted down, and may come to resurface during a meeting with Tacoma Pastures's resident counsellor. But what happens when someone is receiving care? What kind of self-expression is allowed? Is crying or screaming allowed? Even though care is personalized, too much of someone's unique behaviour or habits is looked upon as an interference to care. Giles Perring's study of the cultural phenomenon of non-disabled artists working with learning disabled persons in London sheds light on the embeddedness of our assumptions in various social artistic and recreational practices (Perring 1999). Even though the elderly are not disabled in the same sense of learning disabled persons, a 'deficit' model of personhood arises in both instances. In Tacoma Pastures, bingo for example, was not a therapeutic exercise. The social and recreational activities that were put on as part of Eden were also not 'functional.' Unlike certain approaches to art therapy, whereby the process of experiencing and creating art leads to some kind of healing, old age is not something to overcome. Rather, the trivial and mundane activities were arranged to fill in the emptiness of time in the long-term care facility. There was nothing countercultural or empowering about the disciplining nature of these institutionalised recreational activities.

Fred: The Care Receiver

Let me take a slight turn and briefly explore care from the other side, from the side of the recipient. Kohn and McKechnie tell us that the "view of recipients of care as passive subjects is being challenged on several fronts" (Kohn and McKechnie 1999, 7). Even paying-residents in your average nursing home are more than aware of "[...] the individualization of responsibility and sequestration of experience. The importance of choice, consumption of self-care and self-help is creating new kinds of ways for individuals to experience and participate in their own care" (Kohn and McKechnie 1999, 9). And so, it is with this backdrop that I introduce one of the residents I took care of, and cared for—even after his death—Professor Fred Lieberman.

When I first met Fred, he had just moved to the fifth floor of the nursing home. He was a retired Jewish professor of Humanities and East Asian Culture at the local state university. A couple of things immediately caught my attention. Fred always wore a grey

golf flat-cap, and behind his square glasses, a pair of deep-set intense eyes was always scanning you and reaching for some truth that even you were not aware of. I assisted Fred in the mornings and afternoons, particularly with transferring him out of bed and into various chairs. He could not bend his knees, and because of this he had very swollen calves and feet, to which I applied lotion every morning while wearing disposable transparent latex gloves. Additionally, Fred did not fit my false and preconceived notions of what old people smell like; he was a chemosensory lesson. He ate chocolates like a kid on Christmas morning, and watched Fox News with a set of headphones which he had on full blast—all the time.

Fred took a liking to me very quickly, although I soon found out that he preferred female caregivers. I was only the top of his list regarding male caregivers. Upon learning that I was an anthropologist-in-training, he enjoyed telling me of his trips to Japan and his papers on Chinese poetry and the sociology of the Bolsheviks. As we started to get to know each other more, or rather as we chattered on while I was holding Fred half naked in my arms positioning him unto the wheelchair, he wanted more of my time. This began with him trying to solicit me in helping him write a paper called 'Pee and Poop'. This was his way of wanting to 'get to know how things worked, who was showing up, calling the shots ... there are so many decisions and whispers here'. I knew that his proposal was not serious; he did not have the strength or the focus to write. He did not even have a laptop or typewriter in his room.

Fred became very aware of me trying to read him, and even picked up that I was trying to negotiate a little distance. I was spending too much time with Fred, and I really needed to help the other residents. Two of the women caregivers said that Fred's passive aggressive attention seeking was very hard to work with. To be fair, Fred was not the only resident clamouring for attention, 'customer service,' and time. It was only Fred, however, who pushed his call button necklace incessantly. Our beepers were literally going off every five minutes, and when we came to Fred to inquire if there was something we could do for him, he either looked at us in disgust, or feigned some kind of wheezing condition. On many occasions, I saw caregivers simply ignoring his call button, but rather than give up, Fred turned his attention to the next available caregiver and yelled help!

It was not more than a month after I first met Fred, that I started noticing that he did not help me at all during any of the transfers. This made lifting him incredibly difficult and dangerous. On one morning, I was not paying attention to Fred's usual line of complaints and accusations. As I secured him onto the toilet (or so I thought), and turned away, Fred had managed to pull himself off of the toilet and halfway onto the floor. I immediately rushed to him, and said, 'What happened?' He replied, 'What are you doing?' He looked mean and purposeful; he also added with spite, 'I am dying.' Fred slipped and fell a few more times during my care. Whenever he did so, he would look up and say, 'Are you happy now?'

Fred was a resident who struggled to understand the fragmentary 'system' of care unfolding around him as he tried desperately to evoke empathetic responses from his caregivers. If those who give care do so in a non-reciprocal fashion, their power is overturned by recipients who use time to exploit and challenge the boundaries and regimes of care.

Conclusion

As a key concept, care is contested and articulated at various transitional points and spatiotemporal sites within Tacoma Pastures. More than this, care is transversal in the way that informal and formal caregiving continue to co-exist even though one tends to think that checking someone into a CCRC means outsourcing care completely. It must be noted that while many long-term care facilities do not participate in the Eden Alternative, they are certainly becoming more sensitive to the ambivalence, challenges and complexities surrounding care. Tacoma Pastures is a workspace for formal caregivers, and a home space for residents and their visiting family members who continue to visit them and supplement formal caregiving with acts of informal caregiving. The division between informal caregiving (care provided by family and friends, usually in the context of one's domestic household) and formal caregiving (care provided by paid professionals in a setting like an assisted living complex) is not clear-cut, because care plans do not spell everything out. They are necessary but not sufficient in and of themselves.

This chapter has been motivated by three questions I have been carrying around for a while, and which we may now be in a position to begin addressing. Firstly, why are so many of the residents and working caregivers at Tacoma Pastures dissatisfied with the quality and level of their interactions between and amongst each other? There is a ubiquitous ambivalence over the nature of care. Caregiving can be an invidious task. Part of this has been taken up by the management in trying to adopt new strategies and certifications like the Eden Alternative in order to champion a western inflected idea of individuation and person-centred care. Perhaps, part of reason is that care is a never-ending project; it is not a stable practice because people are ageing and changing all the time. Furthermore, practices of care must square with the fact that people consist of contraries; the field of care, and of need is always emergent and one step ahead of care practices and its various manifestations.

The second question is why has it been hard for Tacoma Pastures, despite some of its limited investment in the Eden Alternative principles and governing practices, to change its ethos? Eden principles have not infused the practice of care in any holistic sense. Eden has been a tag word, and a concept, which via the CCRC's division of labour has been relegated to the recreation department. When Tacoma Pastures first embraced Eden, it went on a mission collecting residents' biographies, hobbies and interests. Nailed to the inside door of every apartment, was a one page 'CV', a summary of that resident's interests, including location of birth and even favourite ice cream flavour. Such information was provided by the residents themselves, and probably with the help of their family members. But these interests were of and in the past. Someone may have enjoyed fishing before, but that was because it was a social activity, an activity between friends and brothers. Simply putting up posters and magazine cut-ups from fishing magazines just did not resonate with most of them anymore. Tim Ingold²⁷ recalled a particular frustrating discussion he had with a GP working with older hospital patients. The GP recognized the importance or rather the linkage between nature and wellbeing, and so he supported having pictures of nature, of waterfalls around. But according to Ingold, this particular GP had missed the mark. Window curtains need to be open, so that patients and residents at long-term care facilities alike can witness that nature is a process and going on outside them and in them. The linkage is not merely a word-game

²⁷ From personal communication with Tim Ingold dated 29 June 2012.

or a style of Pictionary therapy, but rather understanding that when people meld with their natural surroundings, it alters their ontological projections and processes. In this example, the onus is clearly on the caregiver to think about the ontological dimensions of human nature and Nature. Having the curtains and even the actual window open does not mean that the boundary and space between inside and outside is somehow bridged. The point is that human ontology can be expanded beyond the strict confines of an indoor room. This shift in empathic labour is something that Eden has tried to teach various care providers.

Meanwhile, care plans have remained close to objectifying the body, both physiologically and as a kind of bed to be made and cleaned. The care plan gives the basic outline of tasks to be performed, so that even a part-time caregiver can understand the nature of functions to be performed and plan his/her work accordingly. It also, however, objectifies people so that they are, become, what is done to them. Therefore, for example Emily is the cumbersome one (she is picky about how her sheets are made), and Grace is the demanding one, because she requires two and often three people to assist with her mobility transfers. The residents are often defined by what the caregiver needs to do to them, so there is a relational structure indexed to particular care plans, and even how those care plans break down in the face of change.

The last question is, just what kind of organization/institution is Tacoma Pastures? Does it even make sense to regard Tacoma Pastures and for that matter other kinds of long-term care facilities as ideological constructions and bounded instantiations of values, norms and historical configurations of social relations? One approach is that it may no longer be tenable to treat organizations and/or institutions such as the CCRC as bounded entities populated by rational utility-maximizing persons. Instead of trying to figure out just what kind of institution a CCRC might be, the anthropologist is probably better off stepping back, and realizing that the 'problem' and fear of old age and ageing sits out there in society without any formal and/or ritual binding. There are no doubt legal, financial, and secular rituals involved in ageing, but as a concept and a process which is given over to biological and cultural over-determinisms, ageing itself is being re-instituted and quarantined in new contexts such as the CCRC. Being in the presence of the residents and interacting with them under the guise of formal caregiving has allowed ageing to become more than just a discourse or an object of medical gaze. There is a

complex and generative space opening up to critically think about the life course not as a cycle or succession of stages, but as a series of moments of instability and disorder—bringing forth its own re-orderings. This may not amount to an argument about the non-institution (De Pina Cabral 2011), but if care is institutionalized along with the ideology of ageing, persons may not fit into such neat materializations, organizationally or even socially. In Tacoma Pastures, I saw many flowers, some withering, but I could not imagine the garden.

Chapter 8: A Home Away From Home: The Antinomies of Caregiving and Kinship

This chapter presents a comparative ethnographic account of caregiving and social relations arising from two different long-term care facilities (LTCs) in the American Midwest. By looking at practices on the ground, I show how care is conceptualised through an ambivalent set of discourses regarding home spaces, and resident conceptions of family and kinship. As older people are forced to downsize and relocate to new settings, breaking and remaking homes becomes a painful and jarring experience. Despite what memories and ideas of the family might conjure up regarding care and responsibility, the family as a moral and cultural set of signifiers is always present among the residents and caregivers at Tacoma Pastures. The concept of home and the family in light of the Western autonomous self continues to be operationalized through and conjoined by a set of new kinship relations and understandings.

Care for the elderly, and its immediate intimacy and association with dependency, frequently evade the framings of normative Euro-American kinship. For Christine Fry, “kinship is the care network through which one gives and receives varying forms of care across a lifetime” (Fry 2003, 315). In a way, care is becoming too intimate and rationally instrumental. Care sits in an uncomfortable position; there is a tension between the real work of caregiving, and the expectations and exigencies of envisioning what constitutes the duty of family members, and the quality of care they expect from paid caregivers in LTCs.

David Schneider once suggested that in American culture, kinship is biology; the broken heart and heartache are not (Schneider 1980). Schneider was making a point about kinship as a model to live by, which draws on folk biology and biogenetic substance as a cultural construct and an objective fact of nature. In this way, we can understand how kinship is formulated as biology, and that substance forms a code of behaviour. In other words, “Kinship is not a theory about biology; but biology serves to formulate a theory about kinship” (Schneider 1980, 115). Despite this powerful and convincing deconstruction, kinship as evinced in people’s understanding of family in places like the American Midwest, still signifies something people claim to identify with, because the

family represents where one comes from, and relates to who can (and should) ask for and provide care.

This chapter then is also an attempt to investigate how kinship in the context of LTCs comes alive. Because of Schneider's insights, we know better than to posit some kind of natural or cultural grounding for locating the origins of caregiving (Schneider 1975, 1980, 1984). Who you care for and who cares for you might well say something about one's kin relations, but it does not make much sense to ask whether or not kinship *operationalizes* care or how kin-based societies provide enduring care. There is the risk here of reifying concepts. What can be asked, however, is how do people conceptualize caregiving and kinship, together and separately, so that what arises is a social and theoretical space that allows for various practices and meanings. Schneider did address the older agent when he was collecting data on kinship genealogies. In an earlier study, he mentions that the "[...] Image of old folks sitting around doing nothing but counting kin and dwelling on relatives does not gather much support for our [genealogical] study" (Schneider and Cottrell 1975, 99). Despite Schneider's questioning of kinship, he recognised that it could function as a last resort for securing care especially in old age. But this is not always necessarily true. What is missing is an account of how older people come to establish new relations, and how care for the elderly in contemporary western societies is negotiated through the evolving forms and changing character of kinship relations. Too much of kinship studies is focused on procreation, and on filiation and descent: i.e. whom do children belong to and how do they relate to other children and family members in their respective consanguineal and affinal networked universe. To be fair, Christine Fry addresses how caregiving and the meaning of kinship have been changing in industrialised societies. These changes are linked to the labour and consumer marketplace. For Fry, "The care work of kin is contingent on these two markets. To participate in these markets, families have responded by having fewer children, by emphasizing bilateral descent with neolocal residence" (Fry 2003, 331). Fry says, "With affluence, elders and their families may find supportive environments and care in a wide variety of alternative residential arrangements ranging from retirement communities with recreational amenities to assisted living and nursing homes" (Fry 2003, 331). This is underscored by the fact that the service sector in the American economy has been expanding to include caregiving (which involves assistance with the

daily tasks of living along with medical/therapy appointments, supervision of drug treatments and schedules, being advocates, etc.). Fry goes on to say that, “Indeed, one of the first tasks of caregiving when an elder becomes frail is to figure out the services available in the eldercare market and the rules and regulations” (Fry 2003, 328). The upshot is that persons are more mobile as they seek new opportunities in the labour market. This accumulation of wealth ensures that “Nuclear families are not only residentially distinct, but manage separate domestic budgets” (Fry 2003, 326). Moreover, kin in the United States are not typically seen first and foremost as future sources of financial support and reservoirs of labour. Fry’s reading of Bella, Madsen, Sullivan, Swidler and Tipton’s *Habits of the Heart: Individualism and commitment in American life* (1985) suggest that kin are persons, “who have their own trajectories and whose accomplishments are to be enjoyed. Families are fun. Families and households should be the institution of intimacy in an otherwise predominantly bureaucratic society” (Fry 2003, 327).

This is not a chapter about how an ageing ego inhabits his/her kin universe. Rather, I want to explore how caregiving and kinship are ambivalent concepts and kept at arm’s length, especially in the context of LTCs. Is there an analytic relation between the act of caregiving and the formation of new (fictive) kinship systems and relations? Care does not sit in a vacuum, either. Susana Narotzky points to an overlapping of value realms that are economic and non-economic. If the present day practice of capitalism can be associated with an “[...] erosion of relations of solidarity and cooperation [...] this] has significant implications not only for the individual actors but for the capacity of the entire economic and political system to endure” (Narotzky 2008, 12). This ambiguity as Narotzky notes, also leads to the state shedding care responsibilities, “[...] while underscoring personalized and particularistic modes of provisioning support, in a context of increasing self-regulatory practices” (Narotzky 2008: 9). This emerging situation jettisons kinship away from Marxist understandings of household reproduction, and places it in a greater field of affective relations, intimate labour, and new forms of kinship not grounded simply in biological constructions of culture (and vice versa). This chapter draws from two distinct sites. Fieldwork data was gathered at an adult foster care home, which I will refer to here as Grandma’s Place, and is located

just down the road from Tacoma Pastures. Additionally, I will also draw some examples from Tacoma Pastures in order to juxtapose these two ethnographic settings.

A Tale of Two Long-term Care Facilities

The LTC is a catchall phrase encompassing a wide range of institutions that cater to the elderly. Traditional skilled nursing homes are just one kind of LTC; they are usually larger establishments and carry with them specific legal and medical requirements. LTCs are not federally regulated, but are subject to different state laws in the US. Against the more conventional nursing homes in the US, a range of assisted living facilities have begun springing up, serving a host of market and social needs.

Assisted living facilities are a much smaller kind of LTC, and have been labelled officially by the local state government (where I conducted fieldwork in) as adult foster care homes. While assisted living and adult foster care are terms frequently used interchangeably, the main distinction between these smaller boutique style LTCs and the larger and more medicalised nursing homes that operate much like residential hospitals, is that the adult foster care home is an informal home. Adult foster care homes provide residential care in a home-like environment to a relatively small number of elderly persons and those with disabilities who require assistance with the activities of daily living (e.g. cooking meals, bathing, dressing, doing laundry, and taking medications). These services are provided in exchange for some form of monthly payment. To become eligible as an official and operating adult foster care business, those receiving care cannot be related to the licensee or resident manager by blood, marriage or adoption. Furthermore, places like adult foster care homes are not simply bed and breakfasts. In the state's eyes, they must be places that provide residential care. Adult foster care homes are often marketed as places that provide room, board and general supervision of care services in a 'family home.' These LTCs cater to both private-pay and state-pay individuals. For the most part, persons eligible for adult foster care homes must: 1) Be oriented to time, person and place and not a danger to themselves or others in the adult foster care home 2) Be unable to live independently 3) Require minimal supervision in completing some of the basic activities of daily living 4) Be capable of taking action for self-preservation in case of fire or storm with direction and 5) Have some control of

bowel and bladder, but may have stress incontinence and/or be capable of meeting their own needs when incontinent.²⁸

In contrast to the adult foster care home is Tacoma Pastures. To refresh the reader, Tacoma Pastures is a CCRC that allows residents to remain on campus, permitting them to transition internally to differing levels of care. In other words, CCRCs are designed to allow people to age in place. The rationale behind this type of senior housing model is that internal moves within an institution are less stressful than external moves. Medical anthropologist Betsy Pohlman describes CCRCs as facilities in which their

[...] living spaces are configured along a continuum of care and organized through both social and medical models, cultivating a new sort of institutional totality that encompasses social wellness or illness *and* physical wellness or illness. CCRCs include apartments for elders who do not need assistance, assisted living units for those who require some help, and a skilled nursing area for those who require 24-hour attention. Some CCRCs include a specialty unit for those who are cognitively impaired due to dementia. When a person enters as a new resident, it is tacitly understood that she will move progressively, or regressively [...](Pohlman 2007, 5).

Places like Tacoma Pastures are becoming more popular: they are marketed on the basis that once a person decides to join a community, they are guaranteed a place and professional care no matter how they age. In a conversation with the Executive Director of Tacoma Pastures, I was told that, “There is a continuum, life has a continuum and we match services and living spaces with that continuum. Life is a journey, and we are committed to that journey.”

Grandma’s Place

About two houses down from a 24-hour convenience store and nestled behind a sculpture garden of deer, giant mushrooms, and elves enclosed by the ubiquitous chain-

²⁸ Description taken from a local state department of social services webpage: <http://dss.sd.gov/elderlyservices/services/fostercare.asp>

link fence of post-industrial suburbia, Grandma's Place looked like just another working-class house. There were no obvious business signs, although next to the mailbox above the street curb, a sign (with a phone number) was stuck in the ground that read: "Love is the Main Medication." A walkway of stones that snaked behind the garden of hubcaps, faded birdbaths and junk led to a southern style porch, replete with small American flags and pithy wood signs.

As I walked up to the porch, I noticed another less pithy sign hand written in highlighter orange that read: "If sick or coughing, don't come in." I was surprised to be greeted at the door before I even had the chance to knock. I introduced myself by saying that I was a caregiver interested in research on ageing and how we care for our elders. A young woman, who was a former registered nurse, let me in. From the way she moved efficiently and with a dash of assertiveness, I got the impression she was in charge of keeping schedules and running the daily tasks of the home, which included carefully preparing an afternoon snack of Jell-O and canned peaches served up meticulously in glass bowls. The owner, who I will call Grandma, was someone in her late fifties. Grandma was in the kitchen when I first entered, and soon offered me a seat. She was not too surprised at my unannounced visit. I explained to her that I was a caregiver, and an anthropologist researching ageing, and that her sign by the mailbox had piqued my curiosity.

I took a seat, and while still a bit anxious over my somewhat random visit, I remarked that, "this place is really like a home." Grandma said, "Yup. See, this place doesn't smell like a nursing home." I wasn't focused on the two older gentlemen reclined in their La-Z-Boy loveseats, but I recognized the scene. The men were drawing oxygen from their tanks and watching afternoon game shows. I began to take notice of how this ranch-style house was much larger on the inside, and ran deeper into the back than I had initially expected. Some drywall was knocked down to create two large living spaces, both of them proudly outfitted with two brand new flat screen televisions. There was even a study room sandwiched between two bedrooms, with a computer and an Internet connection. Grandma went on to tell me that she owned this house, and that after taking care of her now deceased mother, she decided to go into the business of caregiving, by offering something that was more humane than the nursing home. In her words, she said this was an opportunity "To do it right, the way I see fit."

Grandma told me that she started Grandma's Place in 1984 with space for just six people. Recent renovations, including the addition of a back porch and another garden in the backyard (with a smoking area), meant that Grandma's Place could now accommodate twelve people. Grandma listened attentively and submitted the following: "What I offer is a real home. I take in people for much less money than they do at other places. Not too long ago, a woman came by and was interested in finding a new place for her mother. She had been at Tacoma Pastures, and found that they just left her sitting in a dark room without letting her out. When she came by, and was looking at our place, she cried." I asked Grandma if the visiting woman eventually checked her mother into Grandma's Place. She said, "Yes, but she's gone now." I followed up by asking her and the younger woman, "How long do people stay here for?" After a brief silence, they both said in relative unison, "Until they pass away." The younger woman added, "We have lots of tears here, but also lots of love."

I steered the conversation a bit more by asking how do you make it a home. Grandma took my questions earnestly and told me that she was happy that a young fellow like myself was so interested in ageing and that we all need education. She continued in a very calm and pleasant manner, but shifted her chair slightly to scan the people in the living rooms eating their afternoon dessert. Grandma explained:

The people we get come from all kinds of places. Some are dropped off, others are abandoned. Others have a child or grandchild who come and visit once week. What we have here is love, and they know it. We charge very little for our services, and I always tell people you can't make believe love. You see, places like Tacoma Pastures are too busy. People will just walk over a broomstick if it's not in their PD [position description]. They won't let the nurses sit with people as they pass away, cause they are too busy with their chores, and they don't care. This is disgusting. Some people come here cause they want to be here, to be independent and not dependant on their families. Others can't stay with their children, because they work or bully their own children around with care, and this drains their sons and daughters. Here, these people can't bully us as much, cause we are not family, yet we make them feel they are the boss.

The young woman came back after administering some medication and joined our chat. She said that, "Parents teach kids about ageing and how to treat the elderly. I brought my daughter up well; in fact she is picking a place for me [tongue in cheek]."

Grandma chimed in again:

When some people get old they are abandoned here, and so we are their family. We show love but deep down they know I am not their mother yet we try, and we make sure they worry about each other. This means they are loving and caring for one another, and this keeps their brains working too. This is a job that requires love. This place is about love, and if you don't love old people you shouldn't be in this business.

I nodded and before I left, I offered to help touch up some of the paint that was peeling off the two deer statues in the front yard. Grandma and I stood up, but not before she told me that she was arranging a bus to take her folks to a restaurant in town (a converted old train depot) on Friday for milkshakes. I thanked them for their time and Grandma confided in me, "We need them [the elders] just like they need us." As I was slowly making my way out, I spotted a 70s style poster, purchased most likely at a Christian Bookstore. The picture was flanked by two award-certificates for recognition of outstanding caregiving. In the picture, a transparent Jesus was reaching out to an older woman on a chair. Below the scene, were the following words: "The body withers, we must see what is behind surfaces."

Places like Grandma's Place are not deceiving themselves in maintaining that their home is some kind of idealized household of kin members. Grandma recognizes that her place is first and foremost a business. Yet when people cannot find adequate care or even a place to live in with their own family members, Grandma's Place functions as a haven where ageing persons can feel comfortable showing their vulnerabilities and debilities. Engels' idea of the productive bourgeois household gives way here to a new commodified sanctuary, whereby people no longer able to produce in a capitalist market, must pay their way out of the more traditional and familial household setting (Engels 1972). There is much talk of love, tears, and emotions at Grandma's Place so much so that one wonders whether or not these things actually sustain a kind of narrative that hides what is actually absent, that is caregiving which is not motivated solely by market and economic transactions. It is quite paradoxical that families need to be privatised, that is in the absence of seeking care in one's own household, businesses are literally making family homes. This is not just a matter of 'Family Inc.,' but of the need to materialize certain ideologies (like the family) so that elders can continue creating meaningful relations and transpersonal experiences.

The Tacoma Pastures Family

At Tacoma Pastures, it is important to get along with the residents, as well as fellow caregivers and other staff members. The diverse workforce at Tacoma Pastures includes nurses, med techs (those who have completed training and are certified to administer medication), management staff, various hospice workers (caregivers themselves who Tacoma Pastures outsource when certain residents require extra assistance) and various speech and occupational therapists. The following ethnographic account will demonstrate some of the tensions and conflicts that arise from caregiving on the ground in a CCRC.

Sylvia is a Mexican-American young grandmother who is in her late thirties. When I first started working as a caregiver, I spent my second day training with her. I shadowed her

as she made the rounds on the third floor of the memory care unit. She was pleasant and an informative mentor for the day.

A month passed, and I was now working with Sylvia two days a week, covering for her colleague Diane (a Kenyan woman and a mother of two teenage boys), who was a full-time caregiver. Because I was a part-time caregiver, I also covered for Sylvia's section. On Thursdays, I started working Sylvia's section more regularly, as this was now one of her scheduled days off. From the time I began working in Sylvia and Diane's sections, I began to notice that Diane and Sylvia did not get along. According to Diane, Sylvia was someone who was hard to work with. Diane said to me that Sylvia was obsessed with control. She said that Sylvia was not good at teamwork, and that whenever Diane asked for help, especially in transferring heavier and immobile residents in and out of bed, she was never around and rarely cared to show up. Sylvia, on the other hand, would also make it a point to say out loud, "Hey, you can't leave the foot pedals there on the floor, didn't you go to the weekly meeting?" But when I pointed out one time to her that her resident's foot pedals were on the floor, she quipped, "Well, they are out of the way." Whenever Sylvia pulled the chord, she expected Diane and I to rush immediately to her resident's room.

I also began experiencing snide remarks about how Diane and I did not properly shave our male residents' beards, and whenever she was taking a break or just resting and watching TV (or even eating Tacoma Pastures's food in the small dining room which was forbidden), she would grab a resident from his seat and take him back to his room. In doing so, she would say, "Doesn't anybody do anything around here?" Now, it is true that I didn't always shave my residents thoroughly; yet even Sylvia was guilty of this from time to time. For one thing, electric shavers break down regularly; we always notified family members of this, but it takes time for them to purchase new ones. Finding time to repair the shavers or even to shave them thoroughly with a traditional blade while other residents are in bed, or in a compromised position on the toilet with their walkers far from reach—can be tricky.

Things became more uncomfortable and confrontational when I began taking over Sylvia's sections more regularly. On one occasion, Sylvia blamed me for losing a resident's sheets. Caregivers change the linens and towels on the days the residents have

their showers and skin-checks. The laundry department has been known to lose people's laundry from time to time, but in this case, Mary's family who visit her once every two weeks, were annoyed that they had to purchase yet another set of bed linens. Sylvia failed to mention to me that Mary's family wanted to do her laundry exclusively. Additionally, Mary is uncomfortable with male caregivers giving her showers, and so one day Diane decided to do me the favour of giving Mary a shower. In order to make the division of labour somewhat more fair, I decided to change Mary's bed sheets and towels while Diane was giving Mary a shower. I wrapped up the used linens, and placed a laundry slip in the bag, sending it off to the laundry department in the basement. Mary's sheets did not surface from the laundry department the following week. Shortly thereafter, Sylvia took out her aggression on Diane, by going straight upstairs to the nurse's office, which resulted in Diane having to leave her residents unattended for thirty minutes so that she could try and track down the missing sheets. Sylvia also blamed me for losing the sheets.

Meanwhile, another part-time caregiver named Chloe wanted to change her work schedule from the morning to the afternoon shift. As a result, she moved to the third floor from the first. On one particular Thursday, I briefed Chloe on everything that had happened during my shift. As was customary, I went through the showers I had given, and reminded Chloe of residents who had any outstanding doctor's and beauty salon appointments. I also mentioned that Jean, a recent resident, along with Judy were more or less independent and that aside from reminding them when certain activities and meals times were taking place, that they didn't require anything special. I explained to Chloe that this is what Sylvia told me when she was going over her residents with me.

I came to find out over the weekend that Chloe had actually texted Sylvia, disclosing to her that I said that Jean and Judy were independent, and that we didn't need to do anything for them. Later on, I talked to Chloe about what she had texted. Likewise, I spoke to Sylvia explaining the situation. I reminded her that when I wanted to help Jean with her walker, Sylvia barked at me and said, "What are you doing? She is capable." Apparently I had meddled with *her* resident. I said, "Well since Jean's recent episode, isn't she a fall risk?" Sylvia said, "No, she's independent." So I calmly walked away.

I decided to confront Sylvia about our working relationship and wanted to seek out a kind of truce and mutual understanding. This was unsuccessful. Sylvia did not want to listen to me. I exclaimed, "You have to change. Everyone knows you are a bully, and we have to start working together. I feel as if you are looking for ways to hammer me when I work in your section. I feel on edge." Sylvia responded, "I am a strong worker. You are the one that doesn't work in a team. I heard from the other caregivers that you only pass out cups of water on your side." I said, "We have to resolve our differences and we have to be cool." She said, with a red face, "This is the end of the conversation." Unfortunately, I lost my temper, and stood in front of her, blocking her from leaving the unit to go out and retrieve ice waters from the common kitchen room. Sylvia ran outside and told her sister the med tech that she wanted me out. Her sister yelled at me, pointing her finger, saying that we have a job and why are you bringing up last week's issues? Rather than stand there and receive a public scolding, I went upstairs and told the nurse what had transpired. The nurse said to me, "Just go and work on the fourth floor, we'll swap caregivers for today." The head nurse came to visit me later in the morning and took down my side of the story. She said, try and take Sylvia's side, she is a good worker who has been here for quite a while. After our meeting, I returned to the fourth floor. Right before lunch, the rumour mill started churning. Another caregiver who was also from Kenya, heard what had happened and said to me as we passed each other in the stairwell, "Good for you. It's about time someone stood up to Sylvia. Even the nurses are scared of her."

Dave, the head of the resident centre, approached me later to take down my side of the story. He said that he was trying to be objective and wanted to know how I felt, and whether in my eyes Sylvia was performing inferior caregiving. I told him that she does all the things in the care plan, but she never offers her patients water, she just puts water on the table and it never gets drunk. I also commented that she treats her fellow caregivers very aggressively. I formulated rather spontaneously, "The way you treat others is indicative of your behaviour in general in the neighbourhood."

Before the day ended, Dave decided Sylvia and I should all meet together after work. Stacey, the director of HR decided to come to the meeting as well, and prefaced her attendance by saying that she was not there to fire anyone, but just wanted to see if we could all move forward. Dave and Stacey took out a notepad and instructed us to

describe separately how we felt. Stacey reassured us, "I want you to express how you feel with the other. I will be taking notes, but will shred them after this talk I promise. I always keep my promises."

I started off by saying that I felt Sylvia was very aggressive and a bully. Sylvia protested, "I thought the conversation was done last Friday." I then stated how she once grabbed a resident from the dining room in the morning and took him back to his room. And as she passed me, she remarked, "I gotta shave him cause no one does anything around here." Sylvia pronounced, "I am a strong worker with a strong mind and I have high priorities. I am a woman and I felt threatened by you this morning." I looked over to Stacey and pleaded, "It's not that." Stacey said I agree with Phil, but this is all about how we treat other people. She asked Sylvia how I might feel hearing that "No one does anything around here? Doesn't that belittle his efforts and work"? Stacey then turned to me, "Phil I am not convinced that you didn't do anything wrong either. When someone says the conversation is over, you must respect people's space and not escalate the situation." Stacey instructed me to be careful when using the word bully; "It is a loaded term." She asserted that this episode was a good sign, "It demonstrates that you are both passionate and energized by your caregiving." Dave reiterated, "Life here is characterized by our 'Culture Pillars'. Remember we are committed to ensuring that our elders live happily, healthily and to the utmost of their physical ability. We cannot tolerate conflict among caregivers. These commitments, our pillars, like creating and sustaining a home starts with you guys. This is the human habitat."

Stacey added, "We are interested in the well being of the residents in the community. We are here committed to the journey of life. We are a family; we have to treat each other as brothers and sisters. There are different priorities that caregivers have, and that each person does it differently. We must respect each other's methods." At the end of the meeting, Stacey asked Sylvia and I if we could eventually work together. I said yes, but only if we both changed. Sylvia was more hesitant, and said maybe but not immediately.

Mistakes were made in the field. There were multiple instances where the sheer time pressure of getting ten people out of bed (teeth-cleaned and dressed) within a two-hour window caused me to make mistakes. I left people sitting on the toilet waiting for a fairly long time, while I tended to someone else. At work, I often found myself overwhelmed with stress. I also tore people's thin skin inadvertently when I dressed them too quickly. The stress and the fighting between caregivers was a common theme, which the management tried hard to control. Yet in my mind, the way that we had to inhabit our institutional roles as caregivers in the face of a system we had no easy explanation for meant that we transferred much of our anxiety and fears onto each other.

Nancy Foner's study of the nursing home points to how women rely on kinship ties to obtain their jobs (Foner 1995). Even in nursing homes, Foner shows how women can bring home into the shop floor, by bringing family values and roles to the job. Rather than seeing this as simply humanising the workspace, Foner is right to suggest that bringing in the family can sometimes impinge on work. In a setting like Tacoma Pastures, nursing aides also have to contend with resident spouses and family members who also provide caregiving, albeit informally in an institutional setting.

Even though Tacoma Pastures staff members and directors often refer to themselves as being part of the Tacoma Pastures family, the bottom line is that caregivers are the ones who are more than family member substitutes, their "work draws and builds on and simultaneously reinforces their role and identity as nurturant caregivers in their own families" (Foner 1995, 119). Furthermore, the Tacoma Pastures's directors may say that the caregivers should act as brothers and sisters for the sake of a shared sense of responsibility, but even this has its limits. For one thing, the directors certainly do not want this solidarity to turn into organised resistance.

The caregivers at Tacoma Pastures never talk about or think about themselves in kinship terms with one another. Moreover, the informal rule that caregivers never report to nurses or supervisors did not apply in Tacoma Pastures. If anything, caregivers were scared of messing up in front of their fellow caregivers. An instance occurred at Tacoma Pastures where I was the one being reported on. Jessica, a newly hired Tacoma Pastures

caregiver, reported to the head nurse that I had left July Saunders on the toilet unaccompanied. I was waiting for Jessica to finish helping her resident. I needed Jessie's help to transfer July and I didn't want to hover over her while she was going to the toilet. I thought to myself, July is okay; so I waited right outside her studio apartment, with the door half open. It was not until the end of my shift, that the nurse informed me that I had left July unattended, and wanted to know why. Jessica knew that I did not really abandon the resident. I was outside her room and I even mentioned to Jessica that I needed her help as soon as possible. She knew all of this, and yet she still reported me. Needless to say, I was quite angry and called her ridiculous. To my surprise, I even accused her of not being team player. Jessica said she was concerned about the resident. I said to her: "You should have addressed me first."

The nurse also told me that Jessica had mentioned that I had washed Eunice's hair the previous day and that this was a problem. Jessica, who is a substitute for one of the full-time caregivers on the third floor, said that Eunice's husband likes her hair done exclusively by the beauty shop. Jessica and the med tech had to spend extra time yesterday getting a curler to fix what I had messed up. I told them that this was not in the care plan, and that I wanted to wash her hair because I knew that she goes to the beauty shop only once every two weeks. Furthermore, and I did not say this out loud, but Eunice's husband who comes to visit Eunice in Memory Care about twice a week, wants the caregivers to get Eunice all done up for his arrival. Sometimes Eunice does not want to have to go through the regime of having us put on all that make-up. I ended up telling the nurse that Eunice can be very non-cooperative and can go days at a time without a shower. I had a good rapport with her that morning and said to myself, I will give her a good clean head to toe. Caregivers often reported on their fellow co-workers to the nurses in order to appear concerned and diligent in their work. By trying to give off a good impression, the caregivers that engaged in reporting attempted to carve out a space of relative immunity from future complaints regarding their work and longer than normal breaks.

Tacoma Pastures's slogan, "Committed to the Journey of Life", functions as a euphemism for what is actually going on, that is the institutionalization of the ageing process. The constant monitoring, control, and making of docile bodies in the CCRC sits in a contradictory space, whereby the intimacy of care can never just be about bed and body

work. If care is inevitably and humanely about smiling, showing affection, and empathizing, then the intimacies that obtain between caregivers and care receivers evoke a set of discourses about the family, and what it means to be a social being in the face of ageing. But this idea of the family does not trickle down to the actual residents of Tacoma Pastures. Rather, a fictive kinship ensues which tries to highlight the relatedness of caregivers in the face of their daily tasks alongside the cadres of nurses and directors who oversee and control not only the employees, but the paying residents as well. After all, the CCRC is a space that functions as a home for some, but a place of work for others.

Tacoma Pastures also serves as a civic space; local community college classes are held in its various meeting rooms including a support group to help family members (who do not have any loved ones in residence at Tacoma Pastures) deal with ageing, dementia and Alzheimer's. In these "How to Manage Stress as a Caregiver" support-groups, relationships between parent and child, husband and wife, brother and sister are recast as new relationships and understandings. These support groups offer strategies for dealing with everyday situations, by providing frameworks for compartmentalizing and diagnosing their loved one's conditions. They teach strategies such as creative lying in order to alleviate unnecessary conflicts, especially when short-term memory lapses spiral into uncontrollable repetitions and irrational expectations. Caregivers listen to one another's problems, and shape their own views through the interplay of sympathy and empathy. They are taught by group leaders to enter into the reality of their loved ones—even if this reality is distorted. Participants share their experiences and personal stories, and in doing so they shape their own relationships at home via the support sessions, and what they see as constituting appropriate roles and responses for caregivers and care receivers. Therefore, husband and wife, brother and sister relations are transformed through caregiving into relations of caregiver and care receiver. One also learns from these support groups that family caregivers are hesitant to ask for help from their neighbours and fellow community church members. The tensions between independence and dependence, and the negotiations of personhood around idioms of self-reliance and being able to afford professional care are issues that dominate many support group sessions. Family caregivers are attributed a unique status in these sessions; they are not quite victims, but instead find mutual support and define membership through their hardships and war stories. Their wellbeing is a paramount

issue as well; caregivers are told that they must centre themselves first before they can reach out and connect with their loved ones. The support group rhetoric places emphasis on a particular bounded idea of the person. Therefore, caregiving as a constructed relation with scripted roles, strategies, and priorities are imbued with ideas of self-care, legal capacity, and the function and nature of social relations within the family.

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On the third floor in Memory Care, some of the caregivers were especially territorial in the ways they approached their work. They attempted constantly to assert control over their section and its residents. It was not uncommon for example, for a caregiver to deny his/her fellow caregiver, whose section might consist of the odd number rooms on the other side of that same corridor, from transferring or wheeling *their* resident from the dining room back to the living room area. One time, a resident pushed her call button in her room, complaining that her bed rails were broken. Seeing that her caregiver was helping someone else in another room, I came to the rescue to see what was the matter. The bedrail in fact was not broken, but the resident simply wanted someone to talk to. At this point, I stayed and engaged in a light conversation with her. To the chagrin of the other caregiver, I had overstepped my boundary. Once she came in, she said to me in a brusque tone, "Is everything alright? Ok, I got this from here." She then faced the resident, turning her back to me without any more communication. A sense of ownership also extended to controlling who could socialise and talk to a particular resident's visiting family member. I recalled one episode, where I spoke to a resident's son in the hallway while his mother's caregiver was helping someone else in her section. As soon as the caregiver saw her son and I talking, a look of anger appeared on her face. When the son left, the caregiver told me that I should just mind my own business, and not waste time socialising and abandoning my residents. This example shows clearly that when caregivers get possessive over their residents, issues of territoriality become intertwined with a sense of mutual belonging and identity. When I sidestepped my own section in order to look after another resident, not only was I encroaching upon the other caregiver's space, I was also guilty of abandoning the residents in my own section. Even though the other caregiver(s) did not say anything to this effect, I sensed that what

was being uttered in their negative reactions could have been put into words: “Why are you so concerned with my people? Why are you not taking care of your section, your kin?”

Furthermore, one would think that the holidays, especially Christmas time would reveal at Tacoma Pastures an interesting window through which to view family visitations, and various kinship dynamics. Family members did visit their loved ones throughout the year, but the holidays for the most part did not bring in people or family members from far away. Rather, it was the regular family members who came in week in and week out to collect personal laundry who made sure that their loved ones did not miss out on the holidays. Many of the residents’ sons and daughters decorated their parents’ rooms with various Christmas window stickers and small multi-coloured Christmas lights. For the residents who were still mobile and did not require constant medical monitoring, the holidays meant leaving for a few days to stay with a daughter’s family nearby. For the residents that could not leave to go to a family member’s house they remained at Tacoma Pastures. A Christmas party was held for these residents several days before Christmas day. During the party, residents from the main building and the health and rehabilitation centre convened for an hour and a half to eat pretzels, and drink canned beers and wine while listening to a hired husband and wife musical/comedy duo.

The work schedules at Tacoma Pastures are done in such a way that no caregiver has to work two consecutive Christmases. The major holidays are staggered, so that a caregiver may have Christmases off on the even numbered years, while another caregiver has them off on the odd numbered years. In 2010, it was my turn to work on Christmas day, which was very quiet. During my entire shift from six in the morning to three in the afternoon that day, I recalled only a handful of family visits, including extended family and grandchildren. Nothing special happened that day; it was as if Christmas had already passed, or rather that the party never bothered to show up.

One resident in the centre for health and rehabilitation once said to me when I asked him about why he was trying to call his brother so much, “Family is about communication. And appreciation. When you get older we appreciate what parents did for us, what family did for us. And communication is key for keeping family.”

Because caregiving extends beyond the one-on-one relationship between a caregiver and a care receiver, the relations between a caregiver and a care receiver's family member(s) are also constitutive of the way care is conceived of. To say this is much more than saying that there are various stakeholders involved in the care and welfare of an older person, or that caregiving in a long-term care facility assumes a triangulation or struggle between the caregiver (as broker/mediator) and the resident and his/her family member. For one thing, the family member may be the one footing the bill for the care services and monthly fees, but also the family member of the resident assumes a legal obligation in the instance where power of attorney is invoked in making crucial decisions. Nonetheless, the family member is someone the nurse and management have to consult for certain matters. Sometimes a person who is a long-time friend is elected to fill this role if no available related family member is around. On one occasion, a woman on the third floor whom I was caring for slipped and fell in her room when I was helping someone else. I quickly rushed to her room and called for the nurse as part of the mandatory procedure. I immediately stayed with the resident, but I could not help her up until the nurse arrived. We were taught that in the case of a fall, one could do more damage helping someone up without first assessing the fall, and taking that person's blood pressure, pulse and temperature. Five minutes had passed and a nurse was still not present. I called again, but fortunately the resident did not appear to suffer from any major injuries. She was on the floor, and speaking to me with conscious awareness of what was going on. I went to her sofa and grabbed a cushion for her head as we waited for the nurse. At this point, another resident whose dementia was more severe than the resident who had just fallen was screaming and demanding that there be a doctor present immediately. I had to calm the situation and told her that a nurse was on her way. Finally, a nurse showed up and told me to take her vitals. I had already taken that information while the resident was on the floor and gave her the information on a scribbled piece of paper. The nurse left abruptly without letting me know whether or not to help the resident up to a sitting position. Meanwhile, I went and grabbed a small bag of ice for the resident to put on her leg, as she was complaining about a pain in her upper leg. When the nurse came back, she asked me what had happened leading up to the fall, and whether or not there was any negligence on my part. I explained that I was in another room helping a resident to the toilet, and that I even had my gait belt on. The nurse and I finally helped the resident up. The nurse said that she would probably need

an X-ray, and that we could issue a mobile X-ray but that it would cost her an extra amount. Because of this, the nurse said she needed the family's permission. It was only after a few more hours that the nurse was able to get a hold of the family to order the mobile X-ray machine. The family was not there during the resident's fall, but the medical treatment and the consequences thereafter needed her family's support and acceptance. When I followed up with the nurse later that day about why we waited so long to act, she said, "One of the things I've come to learn and that we've been taught in that recent nurse's webinar is that if you have good relations with the family members, you seldom see law suits."

To shift topics a bit, death was an ordinary event at Tacoma Pastures, but certain deaths sparked controversy, because they put into relief the precarious and imperfect nature of caregiving. Tracy was a resident on the third floor who suffered from mild dementia. She was fairly heavysset, and because of a stroke she suffered several years ago, her entire left side was paralysed. This made transferring her in and out of bed, and taking her to the toilet extremely difficult. Yet even with all of these challenges and mobility issues, she always maintained a cheerful and patient outlook on life. She had a Harvard nursing certificate framed on the wall, from a conference she attended during the peak of her professional life. One day when I was off work, Tracy died in the afternoon. Someone from the hospitality (kitchen and food department) forgot to puree her broccoli, and one of the newer caregivers did not pick up on the mistake. Tracy was brought her food as always on a tray for lunch. This time, however, she choked on the broccoli and died immediately. Rumours began to swirl, and caregivers started blaming Tacoma Pastures for not paying people enough of a salary to keep them employed. According to one caregiver, who also shared my fondness for Tracy, "The high turnover of staff at Tacoma Pastures, and not just the caregivers, is literally killing us."

On another occasion, Heather a resident over ninety-five years old had contracted some kind of a throat and chest condition. She was coughing violently, and could not drink water. The doctor for Tacoma Pastures came in to see her in the middle of the night, and arranged for her to go to the emergency room. Upon Heather's return to Tacoma Pastures just two hours after her visit to emergency room, she passed away in her bed. Over the next two days, her daughter came in the morning and swiftly emptied out her mother's room. Accusatory rumours started to spread. One caregiver said that the doctor

blames the caregivers for her death, because Heather was not properly hydrated. In the doctor's eyes, the caregivers were negligent and not giving the residents enough fluids. This same caregiver said, "That's bullshit. We offer and change waters three times a day." I then chimed in and said, "Well, we do but sometimes we don't and we can't force them to drink." To this the caregiver just looked at me and turned away. Another staff member from hospitality said that the cat, which belonged to a former resident on the third floor, and that was spending a lot of time with Heather, should be given away. He said, "Don't let her go to Mary's room. That cat is the grim reaper."

Summary

I am perhaps coming too close to a constructivist argument about kinship. If as Barnes says, "[...] parents are not necessarily those whose sexual union created the children, but are sometimes those who nourished and raised them" (Barnes 2006, 354), then surely it is not always those children who have to (or even) care for their ageing parents. Places like Grandma's Place prefer to ground care for the elderly in a folk version of kinship which intertwines reason and nature à la Schneider. Viviana Zelizer is right to assert that paid labour in intimate settings causes an abject feeling, especially when people continue to wonder whether paying for care leads to lower or higher quality of care (Zelizer 2010). Maurice Godelier recently said in a BBC Radio 4 interview in 'Thinking Allowed,' that kinship does not give you mobile phones and airports. Perhaps it does not even give you care in old age either. For Godelier, there was never a truly kin-based society. Social relations penetrate and invest in kin relations, altering and metamorphosing kinship structures over time (Godelier 2011).

Caregiving by family members in the home-space brings forth its own set of issues. Siblings are often in conflict over how care is administered, and typically the issue boils down to who will actually do the caregiving. Family caregivers often complain that they are overburdened, and that siblings who are physically closer should offer more support and care. With the onset of ageing societies and the pressures obtaining from changing social, economic and demographic trends in contemporary societies, children and their parents are spending more time together as adults (Harper 2004). Caregiving in this context produces an unsettling role reversal where the sons and daughters assume

parental responsibilities and care for their ageing mothers and fathers. Women are still predominantly the family caregivers, but even this generality is changing. Sons are beginning to move back into their parents' home to provide care not only for their parents, but also for ageing members of their extended family. Old taboos are being replaced by new ones. Washing one's parent and seeing them naked may no longer cause one to blush, but not having enough money to pay for a professional caregiver for one's older parent may actually be a larger source of social embarrassment.

Adopting the recent Marshall Sahlins argument on kinship in light of caregiving does not clear things up either. Sahlins argues that kinship is about, if nothing else, a mutuality of being (Sahlins 2011). Sahlins describes his approach by casting kinship in an intersubjective mutuality of being, and the intrinsic importance of participating in one another's existence. To quote a useful passage, Sahlins says:

The constructed modes of kinship are like those predicated on birth precisely as they involve the transmission of life-capacities among persons. If love and nurture, giving food or partaking in it together, working together, living the same land, mutual aid [...] are so many grounds of kinship, they all know with procreation the meaning of participating in one another's life. I take the risk: all means of constituting kinship are in essence the same (Sahlins 2011, 14).

So what are we left with? Is it enough to say that in the case of the LTCs, caregivers are forming kin relations with their residents because of their conjoint being (caregivers are ageing too), and their performative modes of relatedness? They share the same space, albeit in different ways, but is this enough to say that there is an emerging kinship structure that is founded upon a common experiential interdependence that is shaped by the terroir of intimate labour, empathy, and an ideology of the family?

As older people continue to secure long-term care, breaking and remaking homes will pose policy and social challenges in the future. For the people who eventually check into a long-term care facility, they do so unwillingly, dragging their feet and souls. Giving up the car keys is their first significant act of surrender, and what awaits them is a long list of inevitable losses. What matters for most of the residents in places like the CCRC is a return to home. Home, however, is more than just a functional return to the physical

house they may have once owned. And certainly in many cases, moving in with an adult child's family doesn't constitute home either. Home involves mobility, independence and the ability to affect the world and others. Home is a way station at the end of the day; a place of reflection knowing that you belong, that you have meaningful relationships, and that you matter in the world. Perhaps it is also a place where one best knows oneself (Rapport and Dawson 1998, 9). Even though traditional nursing homes have given way to new options and settings, the variety of LTCs can never be quite like real homes. For one thing, places such as CCRCs are institutions that strip away much of the freedoms and bonds that people associate with in their memories of past homes. Residents in long-term care facilities are constantly reminded of what they are missing. At Tacoma Pastures, even the semi-independent residents are not allowed to have kitchens in their own apartments. These elders are losing their independence, and the various LTCs that actually do the daily and arduous task of caregiving take on an uneasy and ambivalent role. Rather than celebrating the death of the family, in all its idealized trappings, LTCs such as Grandma's Place and Tacoma Pastures have co-opted the idiom of the family. But for whose sake? These institutions have (re)presented familial ideas of solidarity and relatedness as a governing discourse and a set of symbolic elements which constrain the ageing process, eclipsing what it means to age socially. Pseudo-kinship as such amounts to what Janet Carsten refers to as a chimera, produced by the articulations of the state, real family, and the market place (Carsten 2007, 25-26).

This chapter began with an ethnographic account of Grandma's Place. Adult foster care homes attempt to provide a homier alternative to the larger and often impersonal institutions such as Tacoma Pastures. As much as Grandma tried to effect a mother-like persona, at the end of the day Grandma and her staff could never come close to being like family. The situation in Tacoma Pastures was slightly different. Caregivers were not interested in the residents' relations with others. They were there to administer to and prolong the ageing process, even if this meant sacrificing the residents' quality of life. If a resident had a family, this was entirely a private and personal matter. Hence, care at Tacoma Pastures was not just a set of daily and recorded tasks, it was struggling to be rationalized away from a social domain.

In the end, we are left with an uneasiness that cannot be simply swept under the carpet. If care has been outsourced, what then is this new social relation emerging between

caregivers and care recipients? Does this outsourcing act as a kind of appendage to conventional forms of social living, or does it create emerging relations and new social, cultural and emotional regimes? How will care be constituted in the larger social and political economic context in the future? What causes anxiety is not the resident's understanding of kinship, nor the anthropological assertion that the American family is set of bio-genetic relations resting on a cultural notion of biology and blood as an objective fact legalised and naturalised. Rather, the anxiety issues forth when the question of care is linked up with kin relations. Perhaps, that is why there is so much litigation and controversy surrounding practices of care and neglect. One cannot conceive of care in this context without also approaching a cultural and folk evocation of kinship and its categorical antinomies.

Conclusion: Ageing as a Spatial Project and Temporal Process

This study has sought to explore personhood, kinship and social relations arising from the context of a long-term care facility. Even though the present analysis is not an institutional ethnography in the strict sense, a modified and broader concept of practices and institutions has permeated much of my analysis. A broad conception of the institution, as promoted by Durão and Lopes, suggests that we “[...] look at institutions as ingenious combinations of personalities and materialities, where identity and family issues appear side by side with expertise and technocracy instead of treating the two realms separately” (Durão and Lopes 2011, 364). In Tacoma Pastures, we see how issues of care, ageing and relations interact, bringing forth a kind of stability that at once continues over time even as it transforms itself. For the residents at Tacoma Pastures, the ageing process is enacted by various spatio-temporal arrangements and caregiving regimes. People moved to Tacoma Pastures under varying circumstances and for slightly different reasons, but in the end, *someone* chose Tacoma Pastures as a final living destination. Because Tacoma Pastures is a CCRC, i.e. a purpose-built retirement community for residents to age in place, the residents who are there have ceded away much control over their lives. They have done this so that the remainder of their days and nights can be met with some degree of certainty. This certainty stems from the belief that with the help of the staff at Tacoma Pastures, certain aspects of their lives will be sorted out. No matter how they age, and what debilitating diseases lie down the road, they believe that systemic arrangements for living quarters, security, and assistance with medical needs and the activities of daily living will follow them on Tacoma Pastures’s ‘Journey of Life.’

What began for me as an investigation into how people age and inhabit the world of a long-term care facility soon turned into a more focused account of caregiving. My shift in focus was partially the outcome of the fieldwork, and in particular how I came to work as a caregiver, whilst maintaining my anthropological position. Because the exigencies of ageing, arising from the social and cultural context of the American Midwest community, demanded certain exigencies of care, I decided to cast my analysis around the interactions among and between the caregivers and the residents. More specifically, I began to notice how care was conceptualised, broken down and reconstituted daily. Care

was not a structure or discourse that framed decision, but rather provided a touchstone for which the business of ageing and the arrangements for late life formed a unique process. In this way, one can say that ageing at Tacoma Pastures was idealised as a kind of process that could and should be institutionalised. For Kaufman, frailty is what old-age-paranoia is all about, and what we ask of it frames its definitions. She goes on to say that, "It can be understood as a state of being that can be operationalized and measured instrumentally, as a parameter of risk for institutionalization [...] and as a quality and adaptational process, one that forces us to reconsider the meaning of independence and dependence in advanced old age" (Kaufman 1994, 56).

Surely, no other animal infantilises its old. As far as we know, there was never a truly golden age for the old. The old have always been vulnerable, but across varying societies (e.g. gerontocracies), the old have had recourse to a host of strategies. The long-term care facility represents a continuing moment of ageism and old-age consciousness in American society where persons do not have to live under the same roof with people of all ages, or even relatively nearby. The CCRC takes its cue from this particular form of age-grade segregation, and sets up different floors for residents according to social categorisations of age, dependency and disease. Tacoma Pastures is not a microcosm of society, rather it reproduces how society thinks about old age as a collective space set aside from aspects of, and relations in, society. In the context of Tacoma Pastures, care for the elderly contains society's guilt. Is there anything human to ageing? What kind of humanity is expressed in the course of ageing? Is there something universal that might be offered up as humanity in the context of ageing—however constructed? If there is, it has probably become too removed for American society to embrace.

If old age and debility are seen as forming a separate stage in life, one that is segregated and made distant from life's other socially constructed stages, what happens to ideas of the home space? Mowl, Pain and Talbot investigate the place(ment) of the body in the construction of ageing (Mowl, Pain and Talbot 2000). In their qualitative research on the study of older people's lives in Newcastle upon Tyne, the authors found that (gendered) ideas of space had positive and negative consequences. For one thing, home could be a place to assert one's independence. Secondly, confining older people to their homes, where they are expected to spend most of their time, also leads to social

disengagement.²⁹ In the case of Tacoma Pastures, the residents could not live in their homes anymore, especially in the face of increasing ill health and disability. They were either unable to carry out the arduous task of keeping up their homes and/or unable to tend to the activities of daily living without significant help. The home is therefore historically and symbolically important for the residents, and no matter how much Tacoma Pastures tried to manufacture a sense of familiarity and comfort, the residents were left wanting in their new homespace.³⁰

Caregivers did not work to provide a sense of home, but rather focused on providing what Tacoma Pastures called person-centred care. By drawing from a range of corporate cultural pillars and principles inspired by the Eden Alternative, the business of providing care took on, in practice, fluctuating shapes and meanings on the ground. The care plans that the caregivers had to follow could never be fully systematised, nor automated. Instead, care was an assemblage of practices, emotions, and phenomenological excursions into the social nature of being. It was not a right, or a fungible entity one could trade for other services. It defied closure, at once, drawing people together and splitting them apart.

As a concept devoid of context, care is hard to talk about in any meaningful way. Care might be understood as anything that enhances the welfare of at least whoever is receiving it, whether it be in the form of simply listening to someone or providing thoughtful advice. For Kohn and McKechnie, “Care is affective as well as effective” (Kohn

²⁹ Graham D. Rowles makes an interesting point that even though the activity patterns of older people may dwindle, there is not necessarily a contraction of geographical experience. By living vicariously through other and by drawing on social memory, persons can inhabit a geographical lifespan beyond the immediate four-walls of a room (Rowles 1978).

³⁰ In recent times, there has been a shift towards another model called “CCRCs without walls.” Rather than move into a CCRC facility, people can pay for the community to come to them, and at a slightly lower cost. These ‘at-home CCRCs’ dispatch services such as health aids, care coordinators, physical therapists, and visiting nurses to one’s home. People who participate in this model of senior living also have access to nearby CCRCs, including their fitness centres, dining rooms, and skilled nursing facilities (if and when needed). “At-home CCRCs” also coordinate social outings, shopping trips, rides to medical appointments, and consultations regarding safety precautions and modifications for one’s home. The residents in these home-based care programs draw from a larger pool of resources, and as a result they are marketed as a form of long-term care insurance—for those who can afford them of course.

and McKechnie 1999, 1). Furthermore, they state that “‘care’ is very resistant to such clarification because of the taken-for-granted, practical and yet highly emotionally charged nature of caring practice” (Kohn and McKechnie 1999, 1). My observation was that care, considered as a commonsensical and yet abstract term, was also becoming naturalised in places like Tacoma Pastures. To complicate matters further, there is a cultural and moral judgement attached to care especially when one can no longer look after oneself. But even self-care is culturally understood as a particular outcome of a specific and historically-inflected idea of personhood, which is part of and forms the way society in the American Midwest is normatively and discursively conceived of as set of on-going contractual relations, which are not driven primarily by moral commitments anymore. In this way, caregiving for the elderly becomes a drag on the economy, and a problem of social dependency, threatening to challenge and overthrow the zero-sum game that underpins much of the market ideology dominating contemporary American society. The person is therefore left between the opposing forces of independence and dependence. Seeking care in old age becomes a threshold, a kind of social death; the residents at Tacoma Pastures can no longer be allowed to be self-reliant persons.

For the caregivers at Tacoma Pastures, care is infused with a sense of sorrow and pity, in part because they know that society has already cast off as insignificant and obsolete those for whom they care. Despite this, however, there is a breach sometimes to this overdeterminism when residents and caregivers interact which, perhaps unbeknownst to them, recasts their ontologies. Lustbader and Williams offer up a prescriptive example of a caregiving scene that ushers in a rupture to the normative and vacant routines that often obtain between caregivers and care-receivers: “While giving a bath, for example, a nursing assistant may wash a bereaved person’s hair so tenderly that long-pent-up tears emerge and finally receive comfort. Because grief heals when it is received by a caring other, nursing assistants often become central to promoting the mental and emotional health of those they assist [and of themselves]” (Lustbader and Williams 2000, 649). Meanwhile, there has also been a turn to a new age approach toward caregiving at Tacoma Pastures. Therapists work with caregivers to schedule in weekly massages for residents who can pay for the extra services. Here, person-centred care runs parallel with the pre-occupation with sensory therapy and touch. Thomas Kitwood once described the return to our body and its functions as being closer to our life instincts,

harkening back to aspects of our being that are much older in evolutionary terms (Kitwood 1997). Mead reminds us, however, that even though there are some new approaches to caregiving, which challenge and subvert conventional conceptions of health and the body, “[...] our society does tend to prize cognition and executive function at the expense of other essential human qualities: sensuality, pleasure, intimacy” (Mead 2013, 102).

Organisationally speaking, the CCRC is a long-term care facility, where space takes on a certain form of social meaning. This occurs not because the passage of time allows for habitual practices and rituals of interaction to emerge, but rather because the transitions that are built into the system of care articulate specific conceptualisations and figurations of the ageing person. Even though the transitions are supposed to occur within the confines of Tacoma Pastures, the residents have to adapt to new caregivers, residents and novel situations. Rowles and Watkins stress the importance of place-making skills, especially for the elderly. They state that, “Relocation may be particularly traumatic for elders with a history of lifelong residential stability because they may lack place-making skills” (Rowles and Watkins 2003, 80). As I have shown in Chapter 6, these transitions are not so clear-cut, and people often find themselves falling through the institutional cracks.³¹ Habituation becomes sustainable for only so long; there are frequent instances when the residents, metaphorically speaking, find “[...] occasions when [their] automatic pilot breaks down and [they] take an extra step! [and fall]” (Rowles and Watkins 2003, 81). Rowles and Watkins contend that moving to a retirement community for the first time includes transferring one’s conscious memory of past residential experiences along with an implicit bodily memory of how one inhabits space. At Tacoma Pastures, residents often move initially to a room on the first or fifth floors, and bring with them familiar furniture pieces and personal possessions.

The issue of space extends to caregivers as well. In one of the memos sent by concerned caregivers and med techs to the Tacoma Pastures directors and nurses, an outline of issues and possible solutions was offered. For example, some of the issues included

³¹ Tetyana Shippee’s study of social cohesion in a CCRC points further to the fact that different levels of are separated by: 1) the distance between housing units and floor and 2) the types of housing units themselves. She concludes that residents in a CCRC are more segregated and quarantined socially, than one might expect based on the fact that they all reside within the compound of one facility (Shippee 2008).

extending the period of training for newly hired caregivers, improving the communication between caregivers and nurses, and preparing work schedules earlier and more efficiently. Although the floors at Tacoma Pastures were different in their layout, the memo hit upon the point that residents and their visitors often get lost and “turned around”, because every hallway looks exactly the same for any given floor. The concerned employees suggested having the hallways painted different colours. According to an excerpt from this memo: “By painting the hallways different colors it would be much easier to direct people, and it would make it easier for residents to make it home.”³² Given all of this, the issue of space leads to a discussion of time, how the idea of time registers itself in the quotidian context of Tacoma Pastures.

Attending to various conceptions and philosophies of time can illuminate what is at stake in particular practices of eldercare. The CCRC shows how care can be partitioned, resulting in ways time and human experience are likewise institutionalised. The following discussion of time shows that the experience of time itself, as a resource and value, is often ignored by modern caregiving practices. Humans are social, and live with and experience life with others from different backgrounds and generations. Care is part of this social story, and the way humans confront the experience of time. For Nouwen and Gaffney, real care is a confrontation involving care for all ages, because people participate in the same process of ageing (Nouwen and Gaffney 1974). Even though I find such universalisms suspect, I would argue that what is significant is our experience of time and how this experience takes on (or does not take on) a particular form through caregiving. Caregiving can contain our temporal impulses, but it can also release us into the greater exigency of experiential learning and being. Therefore, this chapter argues that caregiving is not just a moral concern for some kind of wellbeing, but should be a commitment to the living as an ontological necessity. As a result, being critically aware of various (and often homemade) philosophies of time will ensure whether or not our elders are being cared for—through certain acts of caregiving—or becoming alienated from the experience of experience itself.

³² The memo was signed and sent to the nurse’s office on 17 April 2011. By the end of my fieldwork, there was still not a response by the directors and/or the nurses addressing the points made in the memo.

This chapter draws upon the CCRC as a scaffold for analysing how caregiving (re)produces certain philosophies of time. The CCRC can be seen as a natural laboratory for exploring the relationship between caregiving and ageing. It also highlights how the institution frames the way time is dealt with. Because the CCRC is purposively built to allow residents to remain within one institution for the remainder of their lives, residents move only between floors in the same CCRC. In other words, CCRCs are designed and marketed as places allowing people to 'age in place.' The rationale behind this type of senior housing model is that moving to rooms within an institution is less stressful than external moves, and that transitions can be better monitored and controlled. As a result, care is segregated according to the nature of tasks, including for example how many people it takes to help transfer a resident in and out of bed. Spatial boundaries are thus erected between floors. Moreover, transitioning to a new floor entails paying additional monthly fees to cover the services charged at the new level of care. For the CCRC, ageing is a process demarcated by stages of care. Underpinning this is a particular idea of dependency and the fear of losing of autonomy. Independence and dependence are idiomatic and structuring principles of personhood in American society, and are always contingent upon historical and social contexts. In a project on perceptions of independence and dependence, researchers found that some people were willing to cede independence in one domain in order to free up time and independence in another (Gignac et al. 2000). According to their research findings, the elderly perceived a greater sense of autonomy despite the fact that they were receiving help in household chores. What mattered was that they were making a conscious decision and link, welcoming dependence in one context, in other to free up time and resources for another. Additionally, Kaufman presents an interesting case study of frailty in order to seek the socio-cultural sources that constitute debates surrounding old age in America (Kaufman 1994). Kaufman shows how frailty reveals American society's ambivalence over issues that straddle independence and dependence. Frailty becomes a condition that persons experience as individuals, while ageing becomes a battle for freedom and autonomy, and set in the opposing forces of independence and dependence. In the CCRC, the push and pulls between autonomy and dependence are constantly being negotiated and reconceived so that a synchronic tension seems to blanket everything.

It will be useful now to venture into a discussion of time, and how certain philosophical approaches can help us re-examine various caregiving practices and regimes. The issue of time, as a philosophical concept, and not necessarily an emic conception of time as being something that one is up against, is rarely articulated or apprehended in a long-term care facility. Time and the temporal nature of human experience, and how this experience is itself experienced by older and ageing residents, receive very little direct attention. It is often said that old age is a foreign country, especially for young people who often fumble to access its customs, language and ethos. Part of the problem, especially in the western context of a long-term care facility, lies with the fact that our everyday metaphysics presupposes that persons live through time, rather than in time. Do human lives take place through or in time? Is there any difference? The philosopher Henri Bergson argued for a philosophy of mobility, of becoming and change, enabling time to be rethought independently of any spatial presupposition. Bergson argues that science treats time as a succession of states unfolding before a pre-existing space. When we count the number of things like sheep, houses over a landscape, or the number of years someone has lived, we are dealing with a pre-imagined horizon of space. But what is this space?

Before diving any further into Bergson, a few words on the anthropological treatment of time, with a nod towards phenomenology, will help orientate the reader. Edmund Husserl's treatment of time, and more specifically his postulation of internal time consciousness, deals with how time and the experience of time appear to human consciousness (Husserl 1966). For Husserl and those aligned with phenomenology, even non-temporal objects presuppose time. In Tacoma Pastures, the issue is not that ageing is experienced as something spatial, but that ageing becomes a spatial project. In Alfred Gell's treatment of time, the subjectivity of time (A-series) connotes the way that events and change are indexed to a tensed existence, involving the past, present, and future (Gell 1992). In contrast to this, Gell draws from Husserl's 'psychology of phenomenology' in order to aid his discussion of B-series time. B-series time orders events in accordance with what comes 'before' and what comes 'after'; B-series may be the 'real' and more 'scientific' time, but it latches itself to A-series time, thus enabling human perception. We cannot directly access B-series time, because it is untensed, and "[...] because all our mental life, our experiences, beliefs, expectations, etc. are themselves datable events,

confined to their localized time-frames, like other datable events" (Gell 1992, 238). Another way to state this is that, "[...] consciousness is understood metaphorically as a flow which is not *in* time, but which is the constitutive source of temporality" (Mohanty 1995, 60). Many of these points raised by Husserl's treatment of retention and pretension as horizons of the present as a kind of extended temporal ontology and Gell's treatment of B-series time, overlap with some of Bergson's ideas.³³

For Nancy Munn, "We cannot analyse or talk about time without using media already encoded with temporal meanings [...]" (Munn 1992, 94) and even though we are in some sense constituted in A-series time, "[...W]e make, through our acts, the time we are in" (Munn 1992, 94). This is not a solution for accessing B-series time, but it does present a kind of practice theory approach towards studying how people construct time-reckoning projects in and through their sociocultural activities and relations. For Bergson, however, and despite time's evasive quality, we can still come close to communing with it, but only through something like the spirit. Where Bergson differs from Gell, and even from the standpoint of a modified B-series theory of time, is that duration as an abstraction can never be made sense of in intervals of dated 'real time' temporal relationships. Duration for Bergson is the manifold substance of existence; the issue is not about temporalisation but actualisation in the non-directionality and non-chronology of duration's flux. Moreover, Hodges points out that Bergson and Deleuze have shown that, "[...] conceptual thought can only constitute a spatialization of *la durée*" (Hodges 2008, 414). And so, where does that leave us?

Suzanne Guerlac contends that what Bergson shows us is that, "[...] we count in space, not in time. The concept of number implies juxtaposition in space. In order for the numbers to grow as I advance in my counting, I have to hold onto the successive images or representation of the units I have already counted, and therefore I juxtapose them with each of the new units I evoke in my mind. The juxtaposition occurs in space. Even when we think we are counting in time, we are actually representing units in space" (Guerlac 2006, 61). For Bergson, this is 'real duration.' Bergson's philosophy attempts to recast our relationship with ourselves, not in some kind of attunement of ourselves to an external world unfolding in space, but in terms of an intuition of ourselves, in freedom,

³³ It is interesting to note that Edmund Husserl and Henri Bergson were both born in 1859.

by taking up oneself in real duration. Bergson argues that measuring time using the intellect, and therefore not grasping it by entering into the reality of time *in time* via intuition, is responsible for many philosophical blunderings. Carr also sympathises with Bergson's philosophy when he says, "It is this unreal time that we have in mind when we speak of our fleeting existence and think of the things that outlast us; it gives meaning to such expressions as eternal youth. Life seems made up of definite states [...] which we pass through, and which we imagine have a period of stability and then change. But the change is continuous throughout each state, and the states are a merely external view of life. It is our body that enables us to take this view. Our body is an object in space, and we consequently regard it in this external way" (Carr 1914, 18). Furthermore, Carr emphasises that for Bergson, "Our life is true duration. It is a time flow that is not measured by some standard in relation to which it may be faster or slower. It is itself absolute, a flowing that never ceases, never repeats itself, an always present, changing, becoming, now" (Carr 1914, 19).

If we take Bergson with a pinch of salt, we come to realise that life framed in this philosophical and metaphysical way does not lend itself to scientific analysis. Yet where science fails and philosophy perseveres, there may still be something to rescue for our anthropological purposes; that is the idea that some human realities may not be penetrated by ethnography (alone), no matter how reflexive our methods. In the language anthropologists are more accustomed to persons are historical subjects. We do not inhabit time, but rather, time inhabits us. This is more than just a snapshot or ethno-theory of personhood; what we are dealing with is a conception of time that is fleeting, continuous and singular in its occurrence, so much so that persons are much more than just the sum of their histories. This is not to say that there is nothing but some fuzzy and abstract philosophical notion of time that inheres in the world, but that when we try to analyse and study ageing as a social and temporal process, we must be aware of the spatial presumptions of reality that occur in contexts like Tacoma Pastures. Further to this point is the idea that when we set old age and ageing within the framework of a life course, we are dealing in abstractions and symbolisations that are not just culturally variable. Hence, analysing life in this way may blind us to seeing how a life is lived, making irrelevant such dichotomies as inside/outside, self/other, and mind/body. This is probably Bergson's contribution to an anthropology of time, in that rather than being

hung-up on distinctions between different orderings of time (e.g. A-Series versus B-Series), the past is carried along through the present to the future, continuously. The present announces what follows, and what is contained preceding it. Therefore life is a ceaseless becoming, and not simply a succession of unrelated slices of time. This is why memory for Bergson is the site of consciousness. A temporal synthesis is required to actualise mobility as action, and not as a thing to be represented on an immobile canvas of space. Along these lines Guerlac says,

This synthesis requires memory. But the point Bergson wants to stress here is that memory does not act like a slide projector, which displays past moments in distinct isolation from one another. It is cinematic. It performs an operation of temporal synthesis. The problem with scientific discourse is that it slices up time and movement into isolated positions, the way a slide projector does. Science eliminates features of experience. It ignores duration, the qualitative element of time, and mobility, the qualitative element of movement (Guerlac 2006, 68).

Given these distinctions, trying to suggest that the experience of time and life is qualitatively differently for an older person is for Bergson a nonstarter. It is a syntax error produced by our linguistic limitations. An old person is old in our governing cultural framework because s/he has traversed more distance, hence space, from a beginning point, which even s/he cannot remember. Yet, there is a legacy of ourselves; we are not born everyday again in some chaotic fashion. For Bergson, "Inner duration is the continuous life of a memory which prolongs the past into the present, the present either containing within it in a distinct form the ceaselessly growing image of the past, or, more probably, showing by its continual change of quality the heavier and still heavier load we drag behind us as we grow older. Without this survival of the past into the present there would be no duration, but only instantaneity" (Bergson 1955, 40). The concept of personhood is not afforded some greater heuristic or existential insight by studying 'older' persons. In fact, old age and ageing are ontologised as matter and memory, so much so that person-centred caregiving becomes nonsensical. Old age is much more than discourse, and acts as evidence for us that time exists externally; that we are all waiting for and wading in time. As residents come to inhabit time in the spatial

organisation of a CCRC for example, we see that they are treated not as persons in time, but as sites of caregiving where persons wage war against time. Even though time and space are inextricably bound, Tacoma Pastures manufactures the idea that its separate spaces, however convenient for the organisation of work for the caregivers as a whole, are a 'natural' function of ageing. Plenty of people grow old and die requiring this kind of caregiving scheme.

Stephen Crites's article entitled *The Narrative Quality of Experience* offers another useful phenomenological understanding of time. Crites argues that, "the formal quality of experience through time is inherently narrative" (Crites 1971, 292). In order to set up his argument, Crites suggests that action is altogether temporal, and that human action, which is subject to being experienced and produced by a conscious agent, has a unity of form through time. Like the specious present, which can encapsulate the duration of a sentence beyond the mere succession of separate words, walking across the room, and gesturing towards an approaching grandchild is for Crites the unity of form through time that can be appropriately called style. Crites goes on to say that, "If style is the form of conscious movement, music is that form purified" (Crites 1971, 293). By treating style in this way, with its inherent musicality, Crites then offers the following relation: "Narrative quality is to experience as musical style is to action" (Crites 1971, 292). Seeing narrative as a cultural form capable of generating experience and meaning, and expressing a phenomenological coherence through time, Crites argues for the primacy of the narrative structure in everyday personal and social life. Without getting too side tracked into a discussion of his ideas of mundane and sacred stories, it is worth noting that stories are not simply arbitrary or whimsical fictions. The narrative forms themselves are fundamental to the way humans inhabit time. The sacred story forms our consciousness, and "[...] projects a total world horizon, and therefore informs the intentions by which actions are projected into that world" (Crites 1971, 296). Mundane stories interact and read into sacred stories, because after all, we live in *this* world and not another.

Crites introduces another dimension to the drama and asserts that, "Between sacred story and the mundane stories there is a mediating form: the form of the experiencing consciousness itself" (Crites 1971, 297). Whether or not one accepts Crites's version of consciousness, it does seem that what we are working with is not just how

consciousness mediates between the sacred and the mundane, but how the form of human experiencing is narrative. For Crites, "The stories give qualitative substance to the form of experience because it is itself an incipient story" (Crites 1971, 297). Indeed Crites demonstrates that the primary ways and forms of experience are narrative. Because we are temporal beings, time can be understood as the way we reconcile in the present the tensed modalities of the past, present and future. This distinction between the past, present and future lends itself to a tension in human life, so that experience is always unfolding. We may recollect the past in a variety of ways, but the successive nature of temporality means that 'forms', like consciousness, are taken up and understood by us in temporal ways. This is what provides the dramatic tension in human life. For Crites, the mundane and sacred stories are necessary for the expression of the tensed modalities of time, and their own sense of meaning and coherence. One can see how personal identity depends on a continuity of experience through time, and what underscores this is the fact that, "Narrative alone can contain the full temporality of experience in a unity of form" (Crites 1971, 303). The narrative quality of experience thus grips the conscious present in a moment of existential predicament between a past remembered and a future anticipated, but still undetermined. Crites draws our attention to this critical modality, which "[...] gives the story a dramatic character as a whole. And since action and experience join precisely at this decisive and critical juncture in the drama, the whole drama vibrates with the musicality of personal style" (Crites 1971, 303).

Although the narrative is a cultural form that expresses, reflects and encapsulates our existence as temporal creatures, Crites warns that the (post)modern condition is a new form of consciousness, trying to break the sense of narrative time. He cites abstraction and contraction as two examples of strategies that are intended to arrest experience, giving it a new atemporal coherence. The abstraction Crites talks about reminds one of the Frankfurt School critique of instrumental rationality and the technocrats' use of population statistics. Contraction, on the other hand, seeks "[...] the particular image isolated from the image stream, to isolated sensation, feeling. The flash of the overpowering moment in which the temporal context of that moment is eclipsed and past and future are deliberately blocked out of consciousness" (Crites 1971, 309). These (post)modern strategies announce an alienation from the narrative form.

Furthermore, the post-Cartesian mind and body have given over to a particular dualism, namely that the mind abstracts from experience what it deems necessary and existential, and the body becomes the locus of feelings—the contraction of an embodiment so that our cyborg selves help us to mediate between what is real and what is phantom. Crites describes the threat to personhood, but not in those exact words, in the following:

Both mind and body are reifications of particular functions that have been wrenched from the concrete temporality of the conscious self. The self is not a composite of mind and body. The self in its concreteness is indivisible, temporal, and whole, as it is revealed to be in the narrative quality of its experience. Neither disembodied minds nor mindless bodies can appear in stories. There the self is given whole [...] (Crites 1971, 309).

More than metaphysics is at stake in this bifurcation of experience against the narrative form. It is not just that telling stories is therapeutic in the usual way narrative strategies are employed in the context of gerontological discourse, but that through the anti-narrative nature of caregiving practices, which attend to the body in its instantaneous form without entering into the world of time with others through the narrative form that structures human consciousness and social experience, people are alienated not only from their experience of ageing, but from life's dramatic tension and musicality altogether. I want to suggest that Crites's argument for the narrative form is inherently an argument about our existential nature in time. For the purposes of caregiving and ageing, there seems to be very little in the way we approach time in places like the CCRC. This is not because it is a secular institution with death denial as one of its services, but rather caregiving seems to have separated temporality into a spatial arrangement so that persons can age in place, according to institutional routines, procedures, transitions and transfers. Providing care for an elderly person is very different from providing care for a baby. People often equate the two, citing overlapping types of dependency, but there are significant physical and ontological differences. Older persons have larger bodies; their skin has a different texture and elasticity. The elderly have also lived longer; their experiences (and affective personhood) are the extended products of a particular temporal trajectory, which babies are only beginning to come to terms with.

One of the ways places like the CCRC can come to grips with the philosophies of time discussed in this chapter is to situate caregiving within an experiential narrative, where the future is embraced and acknowledged with multiple scenarios. For researchers interested in ritual time, Rene Rose Shield's ethnography, hauntingly entitled 'Uneasy Endings', provides a useful case study of how nursing home residents are trapped liminally within an institution (Shield 1988). In her study, the residents do not bond with each other or their caregivers. Because there are no new roles for the residents to undertake, and a lack of *communitas*, the rite of passage is incomplete and residents are left in limbo, jettisoned from time's river. If, however, we look to rectify the situation and focus on how caregiving practices can offer up conceptions of time that lessen the anxiety society feels towards its elderly and the prospects of ageing, the experience of ageing will take on a whole new meaning. Living in time, as Bergson suggests, allows us to respect movement as a metaphysical property and unity through which meanings resonate historically and ontologically. Ageing is fundamentally about how we situate ourselves to one another in and through time. Therefore, caregiving is one of life's experiences. A phenomenology of caregiving sensitive to time suggests that we understand backwards and live forwards. Care is also social and intersubjective. It is not something someone does to another or simply the result of pathology or an instrument of palliation. To summarise, caregiving should be critically reflective of the ways its various practices and regimes measure and hide time. Bergsonian time and thinking about ways to facilitate the narrative quality of ageing can alleviate much of the anxiety and alienation surrounding residents in long-term care facilities such as the CCRC.

* * *

This thesis has looked at caregiving as a set of practices and relations in the context of one CCRC. It has also investigated conceptualisations of care arising from specific contexts that take their cues from particular persons and personalities. At the same time, I have tried to show that these contexts are nestled within the matrix of staff/resident and kinship relations at Tacoma Pastures. These relations can be said to operate in terms of structuration on the one hand, but on another hand they announce something emergent as well, both historically and culturally. I contend that ageing, aside from the arguments on discourse and ideology as material, is made into a process at Tacoma

Pastures when it is institutionalised. I am not concerned here with how the institution of a long-term facility reproduces itself through regimes of care. Of course things are always changing at Tacoma Pastures. New residents and workers are constantly moving to Tacoma Pastures, and even while they are there, situations emerge that challenge the normal course of things. People change: residents lose their spouses, fall down, contract viruses, and shatter femurs. The management staff and caregivers also feel and express the need for change. There are financial and regulatory changes they must address and react to. In this vein, care is not something that can be objectified, measured, and implemented in a straightforward sense. More importantly, care is something that acts as a way to mollify, buffer and filter the plethora of changes occurring at multiple registers. Care at Tacoma Pastures anticipates, however imperfectly, certain trajectories of time and the life course; it is this project of anticipation that is also being institutionalised.

The next point to make explicit, and in summary fashion, is the relation between ageing and care. Ageing in the American Midwest is viewed with much apprehension, and is conceived of primarily as a problem, which first and foremost should be addressed by medicine. The uncertainty and loss associated with ageing causes people to avoid it. People tend to avoid celebrating aspects of change that are part and parcel of human life in its entirety. Loss is particularly hard to cope with. By this, I mean the residents' loss of decision-making, of their control over daily tasks, of their ability to live out their desired lifestyles. When someone loses a particular sense, for example hearing, what is not celebrated is the enhancement of other senses such as the sense of sight. In the context of Tacoma Pastures, what is going on is a lamentation of loss. In the can-do attitude of the American Midwest, the focus is on fixing the problem, and not accepting loss as a welcomed change. Care does not substitute for medical interventions and cures, but provides comfort as a professional service. The caregivers at Tacoma Pastures ensure that the activities of daily living, and the chores of keeping up one's physical body and room are front and centre in this culturally-inflected idea of care as comfort. Not only is one's body of concern, but the resident's room and the state of their bed is brought into the sphere of care at Tacoma Pastures. In this sense, self-care is not just symbolic, but also can be detached from one's personhood. Care objectifies aspects of the body and

one's immediate environment, freeing the culturally-inflected and ageing soul for ontological respite and relief.

The third point is what to make of the relation between professional (formal) caregivers and care receivers. Conventional wisdom suggests that family caregivers are somehow better caregivers, because they know and love their elders. Yet, there is the also idea that sometimes, family members are too emotional and close to their loved ones, making it hard for them to provide objective and effective care. What is the right distance then, and what does this say about the kind of intimacy and empathetic/emotive space being carved out by new forms of caregiving relations. This thesis has gestured toward exploring this aspect for further research. How people ground these emerging relations, especially in late life, is ontologically interesting. New subjectivities and commitments will continue to evolve no doubt.

Lastly, the residents at Tacoma Pastures are not victims in the jerk sense that somehow the long-term facility has injured or taken away their personhood. Neither are they victims in the sense that society has offered them up for sacrifice in some kind of ritual arrangement. Rather, they are victims because they have been duped into thinking that life can and should be arranged and sorted, especially in old age. Many questions remain unanswered, and some have yet to be formulated. One question that I have not yet adequately answered is whether or not we can say that there is such a thing as a 'bad caregiver'. In the face of human vulnerability, and given the fact that much of formal caregiving, at least in the context of American long-term care facilities, is reflexive across social and generational boundaries, and evokes certain ontological and relational commitments through empathy and vicarship, the probability of an amoral and indifferent caregiver seems unlikely. Caregivers are more than just manual labourers; they may also be moral agents of change. Their work cannot be viewed without this moral and emotional context. It is perhaps a mark of our evolutionary history that the longer we live, the more social and interconnected we find ourselves, and that money isn't really everything—even in the business of ageing.

Appendix

Ethics Form



University of St Andrews

University Teaching and Research Ethics Committee

29 March 2013
Philip Kao (080012476)
Department of Social Anthropology

Ethics Reference No: <i>Please quote this ref on all correspondence</i>	SA9761
Project Title:	An Ethnography of a Continuing Care Retirement Community (CCRC)
Researchers Name(s):	Philip Kao
Supervisor(s):	Professor Christina Toren

Thank you for submitting your ethical application form which was considered at the Social Anthropology School Ethics Committee meeting on 15/4/13. The following documents were reviewed:

- Ethical Application Form

The University Teaching and Research Ethics Committee (UTREC) approves this study from an ethical point of view. Please note that where approval is given by a School Ethics Committee that committee is part of UTREC and is delegated to act for UTREC.

Approval is given for three years. Projects, which have not commenced within two years of original approval, must be re-submitted to your School Ethics Committee.

You must inform your School Ethics Committee when the research has been completed. If you are unable to complete your research within the 3 three year validation period, you will be required to write to your School Ethics Committee and to UTREC (where approval was given by UTREC) to request an extension or you will need to re-apply.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical consideration, must be reported immediately to the School Ethics Committee, and an Ethical Amendment Form submitted where appropriate.

Approval is given on the understanding that the 'Guidelines for Ethical Research Practice' (<http://www.st-andrews.ac.uk/media/UTRECguidelines%20Feb%2008.pdf>) are adhered to.

Yours sincerely

Convenor of the School Ethics Committee
Ccs Supervisor
School Ethics Committee

OR Convenor of UTREC

UTREC Convenor, Mansefield, 3 St Mary's Place, St Andrews, KY16 9UY
Email: utrec@st-andrews.ac.uk Tel: 01334 462866
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Poems

A few poems I wrote during fieldwork:

Morning Care

"The long day wanes: the slow moon climbs: the deep / Moans round with many voices"
(Lord Tennyson's *Ulysses*, 55-56)

Like the Galaxy
The old keep secrets too
Tucked away in forlorn corners

In your universe you are light, but in mine
You are not even the moon
But a pure magnet.

You sleep
Knowing that I am there
Breathing

And you see in your dreams already
That death is life in reverse and so
You climb back into the deep

For that's where the children
Laugh with their whole bodies flickering
Like butterflies on fire.

I watch you sleep like a lover
Watches his soul sleep
On the rise and fall of the sheets of his lover

We must be free falling
But you do not protest as
A snowdrop pokes above the ice field

To enter your world in silence
Is to smile in the dark
But in the light I cry for I can only bring you water this side of the horizon.

A Room with No View

In the corner room
On the top floor of
A nursing home
We call the 'health house'

A drawer of hidden
Memories rests dormant
In a thrown-away
Dresser. Pull it out — gently.

Discover a brittle
Blue poker chip,
(Perhaps from an infamous Bingo
Game)

Look and see a folded letter
Badly typed but never sent.
A worn out pack of finished Paul Malls
Next to a picture of wife and husband
Turned face down.

I turn towards you like a robot
You blink, I think.

Another revelation of a monument beholds:
In my shame, a perfectly pulled
Hospital curtain track system.

Who can endure the whisper of a blurred existence?

The oxygen concentrator
Purges our chasm with vents
Of stupid sporadic visions.

The Uncertified Caregiver

She's drooling again in her sleep
With her left foot dangling just there.
I sit in old scrubs tired of the lifting
Looking with half-ass care.

Someone died today just as they woke.
I say
"Frost happens to flowers."
Who's got time for time, when you're broke
In your car crying at power?

In the heart's eye, no picture of happier times
No family in their canoe.
I loosened the skin of my crime
And rendered me in your arms too
newly dead.

A Blue-Gray Raga

Some places the smoke flies
And tall wild rice
Slalom sweetly
Swaying to the music of the melody moon

But this is not Detroit nor a
Youngstown, bless those forgotten scars
My city, she sings and sings
Can you hear her?

She has wintry skin
And abandoned parking lots with
White shadows
Salting her wounds

Brown river and gray sky
Touch in the streets
And east coast bandits
Whisper to their unborn:

"We are the food bank now, the
Fish bullied by the river's currents.
Our pantry packs are court ordered
Gifts for warehouse workers"

In this poor theater will you too
Die in Sparrow,
Alone, clinging to dreams of copper mines
And a love before Thoreau?

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