Introduction

Care Home Stories

Aging, Disability, and Long-Term Residential Care

Sally Chivers and Ulla Kriebernegg

This book is motivated by the need, in the face of population aging, to tell new and better stories about institutional care. We take a close look at the stories that circulate both in the popular press and across forms of more imaginative popular culture in order to understand social, cultural, and political messages that attach to what are commonly called "nursing homes." We gather stories from people who have worked and lived in long-term residential care that capture the rich interplay of subjectivities and the complex relationships that emerge in those spaces, both of which depend heavily on context.

Whether in a nursing home, care home, retirement home, assisted living, or other form, institutional care for seniors offers a cultural repository for fears and hopes about an aging population. While people adamantly desire to age well at home, without making the big move[1] to render their latter years more manageable, and policy makers play to that desire, apparently buoyed by how it offers them an opportunity to download the costs of care onto the family unit, the fact remains that many contemporary senior citizens will require institutional care, and some might even choose it. Enormous changes have occurred in how institutional care is structured, adapting models from the poor house through the hospital to the home and the hotel and the village. But the legacies of the poor house and the hospital persist, creating panicked views of the nursing home as a dreaded fate for people who may actually benefit from new living quarters in late life. The paradoxical nature of a space meant to be both hospital and home offers up critical tensions for examination by age/ing studies scholars. In this book, we gather imaginative critical and personal essays that challenge stereotypes of institutional care for older adults, that illustrate the

1 | Famous gerontologists Anne M. Wyatt-Brown, Helen Q. Kivnick, Ruth Ray Karpen, and Margaret Morganroth Gullette reflect on the transition into a Continuing Care Retirement Community in *The Big Move: Life Between the Turning Points*, Indiana UP, 2016.

changes that have occurred over time, and that illuminate the continuities in the stories we tell about nursing homes.

We want to change the script, in part, for Rhonda, the fictional character depicted on our book cover. The short Canadian film "Rhonda's Party" portrays the collision of the unexpected with the predictable in the life of what we are calling in this book a "care home."[2] Rhonda doggedly prepares for her friend and fellow resident's 100th birthday party while, unbeknownst to her, staff are signing papers that verify that her friend has died. The film lingers over choices about whether to continue with the party ritual to cover up the markedly bureaucratic form-signing rituals that punctuate death in the long-term care environment. Those contrasts are mirrored by visual contrasts in the cover image, between Rhonda's serious face and the celebratory joy implied by the balloons, between the colourful round curve of the party balloons and the rigid dark lines of the corridor. Such potentially generative tensions permeate our book, which uncovers many ways in which the enforced rigidity of care home spaces is challenged by an undeniable infusion of humanity. Most importantly, Rhonda's firm gaze at the camera reflects the centrality of the human experience, in all its variety, in our thinking about care home stories. Our humanities perspective enriches a domain too often dominated by purported economic exigencies.

The need to tell and analyze care home stories intensifies due to this era of New Public Management in which care homes currently operate. For example, immediately upon entering a "care centre" in the Canadian province of Ontario, visitors encounter a "Strategy Map." This sign is the very first thing people see in what is advertised as a *homelike* atmosphere. Using corporatized language, this "map" explains how "Know How" leads to "Internal Processes" that benefit the "Customer" leading to "Financial" gains. These elements are pictured as all working together towards "strategic goals" of being *bigger* than other "retirement lodges" and the conglomerate that owns the care centre becoming the #1 choice in Long Term Care the following year. The map flows into a final coloured box which articulates a "Big Hairy Audacious Goal": "to become the

2 | The nomenclature of "care homes" is thorny enough to merit its own chapter. While "nursing home" is commonly used in North American popular contexts, it means different things in different jurisdictions. Not all the spaces we explore in this book include nursing, though all have to do with some form of paid or unpaid care work. While we don't ignore the institutional legacy of these residences, we don't want to unduly focus on that aspect of long-term residential care, itself an unwieldy phrase that conjures up unpleasant associations for some constituents (for example, indigenous people in Canada who were forced into residential schools). We have chosen to think about care home spaces and care home as a term, for all it evokes, in this book, though the other terms show up in relevant contexts.

Company that most changes the image of seniors' services from a necessity to a desire by 2020."

On a personal visit to that care home, when Sally chatted with another visitor, that older woman openly gestured to and scoffed at the sign, asking, "What does *that* have to do with me?" That question has stuck with us as we have gathered personal and scholarly reflections about Care Home Stories. The chart regretfully has everything to do with the older woman visitor because it reflects the values of the institution where she has had to choose to place her husband – this is a relatively fancy non-profit institution, not a last resort among last resorts. The people who work there are forced to appear to think in terms of the large boxes – "know-how," "internal processes," "customer," and "financial" – so that their employer can grow. Added to which, they work, and he lives, in the most highly regulated yet worst funded sector in Ontario, causing them to do more charting than body work.

The "Strategy Map" tells that story and not myriad others that the visitor might desire and immediately be able to place herself in. This book seeks to contextualize that currently dominant story of long-term residential care: the one that appears on the surface to have nothing to do with the people who live there and the people who love them. We put that version among other stories of everyday life in and around care homes. We want to know as much about Rhonda's party preparations, her anticipation of a friend's remarkable centenarian celebration, and her imminent grief as we do about the hospital-like corridored setting, the imposing nursing station, and the bureaucratic mechanisms that manage death in the care home where she lives.

We have gathered the stories and studies in this book because we believe that we do indeed need to be audacious in setting goals for changing long term residential care. But different contexts need different goals, and so we should not narrow ourselves to one Big Hairy Audacious Goal. We need to think about what values underlie the systems in which long-term residential care operates, beyond those that situate seniors in need of care as "customers" who contribute to or sap "financial" viability. Instead of aiming to grow our business to become number one, and instead of supporting the notion that public institutions ought to be run like businesses, we should all work together to think about many different ways in which long-term residential care in late life could become something desirable rather than necessary.

Why Care?

While thinking about care might seem to limit what we imagine later life to be, the question especially of long-term care propels social and cultural meanings of population aging. When the popular press is overwhelmed by negative

images of older people, it is not just evoking fear about what each person's fate might be – a deep fear of physical change that could bring pain and restriction to the activities of daily living, not to mention raising the spectre of death. Beyond that, images of older adults overtaking youth – often pictured as a giant wave – are about dependency. The idea that younger generations will have to do the work of care and, worse yet, pay for care is a significant portion of what makes such demographic projections play apocalyptically. Thus, we focus on care here because it is at the crux of age/ing studies. Changing the meaning of care stands to substantially change what it means to "age well."

Why Home?

Home appears throughout understandings of long-term residential care as an unquestioned ideal. The notion that institutional settings are improved when they are homelike goes virtually unquestioned. Not only is that assumption worth up-ending, so too must we question whose home these spaces are meant to be "like." As Annmarie Adams and Sally Chivers point out in the context of design, "how to capture and conjure up an image of home to residents of various backgrounds" poses a "perennial challenge" (138). It is, perhaps, easier to pinpoint what is *not* homelike than to effectively describe let alone manifest homelikeness. We focus on home here because it is held up as an unquestioned good, particularly in policy documents that stress the widespread desire of people to age in place, meaning in their homes. But home is a thorny concept that benefits from interdisciplinary and international scrutiny.

Why Stories?

In *The Truth about Stories*, Thomas King famously states, "The truth about stories is, that's all we are" (2). Yet care homes are not usually thought of as sites for *new* stories – instead the people who live within them are thought to be vessels for stories of a past from before they made the "big move." We turn to stories to put the key terms of "care" and "home" together because they offer a meaningful and aesthetic way to contain and revel in multiplicities. A story can offer a few vantage points without taking a side but a story can also effectively and convincingly play favorites. There is no need for objectivity but rather a helpful indulgence in productive subjectivities. We think there are new stories to tell regarding care home spaces about, with and by the people who work, live and visit them.

The Contributions

The 16 chapters collected in this volume, together with five poems, each in its own way, challenge dominant understandings of institutional care, thinking through how it has changed, and elucidating what has stayed constant in Care Home Stories. They seek to answer questions such as, how do stories about care homes challenge existing or create metaphors for institutional care? What stories do people living or working in care tell? Who tells care home stories, and who doesn't get the chance to? How do people think they know what care home life is like? How are care homes represented in poetry, film, art, fiction, and popular media? And how do these stories change views about institutional care?

The book consists of four main sections with four chapters each: "Personal Perspectives," "Working and Playing in the Care Home," "Literary and Cultural Perspectives," and "Social and Historical Perspectives." Additionally, Betsy Struthers's poetry about her own mother's dementia and death in a care home helps structure this volume: each section is preceded by one of the five poems she kindly agreed to share with us. "The Push" is our prologue because it beautifully connects a very specific moment in time, a woman visiting her mother in the care home and taking her for a walk in her wheelchair, to our constantly changing roles and positions throughout the life course. More importantly, it emphasizes the importance of intergenerational connections and care at every moment throughout our lives.

The book's first section, "Personal Perspectives," comprises subjective experiences with institutional life. It is preceded by the poem "Pretty Little Angels," which offers a very personal account of a difficult visit in a care home. By describing the unpleasant hospital-like atmosphere of the facility with its elevators and nurses, its pastel colors, plastic vases, and disinfectant smell, the speaker conveys the uneasy feeling entering such a surrogate home entails. The ironic twist at the end of the poem almost offers some comic relief, but it still hints at the difficulties and ambivalent feelings that accompanying one's parent through the last stages of their lives may bring about. In the opening chapter that follows, almost weekly triangular care-home visits between 2008 and 2011 with her mother, her mother-in-law, and her good friend Robert Kroetsch are at the center of Aritha van Herk's creative non-fiction meditation "At Home or Nowhere: In Memoriam – Pat Sharp in Edmonton; Marretje van Herk in Edmonton; Robert Kroetsch in Leduc." She offers "a personal exploration from the perspective of a family member and friend who watches and engages the 'care home' from without," as she describes it in one of her initial email conversations with us (van Herk). She not only offers an account of her relationships with these three aging and increasingly frail persons but also shares, in her very own poetic voice, her reflections on how these "explorations into the heart

of oldness" shaped her own ideas, fears, and imaginations of growing old. In the next chapter, "Home Interrupted," Monique Lanoix examines how institutional care offered to younger individuals makes it difficult to feel at home in an institutional setting. She tells the story of her husband's institutionalization in a Québecois care home upon a severe accident that left him severely injured and in need of long-term care. Lanoix draws out her experience of the institution's liminality and transience, analyzing how in addition to the spatial setting, daily practices of care continually emphasize the "not-home" within the living environment, creating what she calls "two-home syndrome." She argues that homelikeness cannot be produced and maintained by the physical environment alone, but should be inscribed in the practices of care. This interest in possibilities for improvement also characterizes Amanda Barusch's chapter, "A Place for Dad: One Family's Experience of For-Profit Care," in which she reflects incisively on the challenges she had to face when her father, who lived many hours away from her with his second wife, was diagnosed with dementia and needed care that his wife could no longer provide herself. Barusch, an academic gerontologist, documents the process of gradually moving her father into institutional care with sensitivity, including personal e-mail conversations with Catherine, which underline the challenging role Barusch found herself playing. Barusch contextualizes her personal story with a very informative overview of the development of long-term care in the United States. In the final chapter of the section, one of the rare first-hand accounts of what it is like to reside in a Continuing Care Retirement Community is provided by Anne Wyatt-Brown in her essay "Life in a Continuing Care Retirement Community: On Not Being Invisible." After outlining why she eventually decided to move to Roland Park Place, she addresses the challenges this transition has brought about for her by juxtaposing her own experience as a gerontologist with self-help books, such as Stephen Golant's, on where to live in old age. She reflects on her struggle to keep her autonomy and independence by reporting about how she and her fellow residents, who had become her friends, reacted to the change of staff in the Roland Park Place's fitness center, a place of crucial importance to her as it had given her a sense of belonging. She argues for the need to combine gerontological knowledge with personal observations in order to help others make good decisions on where to live in old age.

Section two, "Working and Playing in the Care Home," is prefaced by Betsy Struthers's poem "Second Sitting,"[3] which contemplates the lack of personal attachment and friendship in a care home and emphasizes the anonymity shared by its residents. The four contributions that follow center on personal experiences and on-site research that has been conducted in care homes, albeit

3 | An earlier version of "Second Sitting" was previously published in *Sugar Mule* 33 and is reprinted here with permission.

from very different perspectives. In "Shelter in Place," Laura Dunbar shares a perceptive and poignant personal story about how she got be a nurse, how she started work at a nursing home in Ontario, and how she struggled with reconciling her daily duties in a highly regulated institution with her sense of what adequate professional and personal caregiving meant for her. With her piece, she lends a voice to the many nurses and nurses' aides in care homes who are usually underrepresented in research despite the fact that the quality of care largely depends on them as they try on a daily basis despite adverse conditions to help their clients maintain their dignity, and to treat them with kindness and as human beings. The centrality of caring, personal relationships at all stages throughout the life course is also at the centre of Peter Whitehouse's article, "Long-Term Care for the Future: Just What is Real Anyway?," which offers two stories about what he calls the realities and unrealities of care. His account is based on the one hand on his experience of living as a part time resident/researcher in The Terraces, an independent/assisted living facility that is part of Baycrest Geriatric Centre, Toronto. On the other hand, it tells about Whitehouse's visit to Hogewey, a long-term residence in The Netherlands for people with dementia. Sharing the story of what has shaped his view on dementia care and drawing conclusions from his on-site research, he argues for a change in our understanding of long-term care that focuses on intergenerational learning in order to create resilient communities that can face the social, economic, and ecological challenges ahead of us. New perspectives on dementia care are also offered by Julia Gray, Pia Kontos, Sherry Dupuis, Gail Mitchell, and Christine Jonas-Simpson in their co-authored chapter "Dementia (Re)Performed: Interrogating Tensions between Relational Engagement and Regulatory Policies in Care Homes through Theatre," which aims at disrupting the tragedy discourse that informs cultural representation as well as policy making. Presenting two scenes from their research-informed play *Cracked: New Light on Dementia*, they show how theatre productions can intellectually *and* emotionally engage audiences. *Cracked* was developed to open up a playful, social space to raise questions about current conceptions of dementia, expose unjust care practices and policies, and facilitate envisioning and inspiring an alternative care culture. Their analysis is framed by the personal/professional experiences and research that informed the scenes' development, as well as post-performance evaluation data where dementia care practitioners discuss specific scenes as catalysts for change. Similarly, Aynsley Moorhouse discusses how theatre can facilitate new approaches to long-term care: In "'Hooray for You and Me': The Story of a Theatre Group," she illustrates how she developed and implemented a five-month theatre and digital storytelling group for residents of a care home in Toronto, Canada. She adapted an online blog for the chapter, guiding readers through the development process and sharing her personal observations on

how the production took shape. Her blog thus became a relationship-centred document that tells a care home story full of joy, laughter, creativity and growth.

Betsy Struthers's poem "My Mother Defines Purgatory," opens section three, "Literary and Cultural Perspectives." The poem offers a limited inside point-of-view of an old woman waking up slightly confused in her care home bed. She is helpless, disoriented, and desperate, also because the care she receives lacks compassion and does not fulfill her need for affection and kindness. On the contrary, she feels humiliated. The poem, like many fictional texts set in care homes, also criticizes the lack of privacy in institutional settings and, in a nutshell, describes what is commonly understood as "the nursing home specter." While some works of fiction centre on the lack of agency, however, others portray old people as "active agers." In her chapter, "The Third Age in the Third World: Outsourcing and Outrunning Old Age in *The Best Exotic Marigold Hotel*," Amanda Ciafone turns to cinematic portrayals of old age as a time of affluence, self-determination, and activity. She explores old age through a critical reading of post-colonial theory and discusses India as the setting of these stories. Her text centres on the argument that the country is coded as exotically 'other' in order to portray the old characters as living the ends of their lives fully: they meet new lovers, build familial networks, and find new professions and passions. These life developments in old age are made to seem exceptional, then, and dependent on a fantasy backdrop to play out. A more realistic background is presented in Peter Simonsen's chapter that investigates how, in Ian McEwan's novel *Saturday* (2005), risks of terrorism and dementia are curiously parallel. It is typically read as a novel about the everyday fears and constant worries that entered many individual's lives in the aftermath of the terrorist attacks of 9/11. This has shielded us, Peter argues, from an equally important aspect of the book: the way in which it captures the growing fears and constant worries entering many of our lives that we will end up as dementia patients. Patricia Life in her chapter "Outside the Nursing-Home Narrative: Race and Gender Exclusions in *Green Grass, Running Water*" then considers what types of texts are missing from what she calls the nursing-home-narrative genre and what types of people are absent from nursing homes. People such as the four old Indigenous patients who run away from the care home in Thomas King's *Green Grass, Running Water* are excluded, feel excluded and/or exclude themselves from residency in Canadian institutions. Life's study of King's text reveals a need for age theorists and governments to address the thorny issue of intentional and unintentional segregation of care according to race and gender. Katrin Berndt and Jennifer Henke explore in their co-authored chapter "Love, Age, and Loyalty in Alice Munro's 'The Bear Came over the Mountain' and Sarah Polley's *Away from Her*" how the short story and its film adaptation deal with questions of commitment in a lifelong marriage challenged by the effects of dementia and the female protagonist's move into a care home. They approach

both works from a narratological perspective and investigate how both fictional representations of love, loyalty, age, and dementia invite a reading that emphasizes a new beginning even at a late point in life.

"Rising Fog," Betsy Struthers's poem about saying good-bye to a mother left behind in an unpleasant care home, initiates the fourth and last section of the collection, "Social and Historical Perspectives." This last poem finishes a kind of narrative arc from ambulatory to bedridden, and starts by quoting Emily Dickinson's famous last words: "I must go in; the fog is rising." The lyric I, a daughter who is sitting on a bus on the highway, returning home from a visit with her frail mother, finds herself haunted by the vision of her mother's clenched fists and stare when she has to leave her behind. She tries hard to concentrate on what she sees outside: an owl, crows, geese, the lake, and rising fog: over the lake, the moraine, and from her own breath on the bus's window pane. The fear of an old age defined by decline, dependency, and the loss of agency that Betsy Struthers expresses through her poetic voice is addressed from the perspective of sociology by Chris Gilleard and Paul Higgs. In their chapter, "An Enveloping Shadow? The Role of the Nursing Home in the Social Imaginary of the Fourth Age" they argue that the nursing home is both a site and a symbol that fashions the social imaginary of a fourth age as it plays a pivotal role in articulating the fourth age, the practices that play out under its shadow, and the contradictions caught up in its denial. In the next chapter, Marija Geiger Zeman, Zdenko Zeman, and Mirela Holy present a sociological reading of a Croatian novel in their analysis "A New Home, A New Beginning, A New Identity: Old Age, Life Narrative and Self-Presentation in the Novel *The Real Captain's Sea* by Zvonko Todorovski." It focuses on literary presentations of institutions of older persons, gender roles, and images, by which, finally, the questions of identity, and dramaturgic, relational, emotional, and ontological aspects of life narrative come into play. In the following chapter, spaces and places of care are at the centre of Isabel Atzl and Anamaria Depner's text "Home Care Home: Reflections on the Differentiation of Space in Living and Care Settings." Using an inductive approach, they analyze from an interdisciplinary perspective the role of objects in past and present nursing and care settings. They discuss how nineteenth century nursing textbooks describe how patient rooms should be designed and set up to be in line with the medical guidelines of the time and compare them to state-of-the-art textbooks. Also, they include excerpts from a field report to portray an example of daily life in care facilities. Finally, James Struthers's chapter "Home, Hotel, Hospital, Hospice: Conflicting Images of Long-Term Residential Care in Ontario, Canada" rounds off the collection. He explores a series of recurring stories about care homes that featured prominently in policy discourse and in the media primarily during the post–World War II era in Ontario and traces the

development of caregiving institutions and their discursive framing from the poorhouse to modern-day facilities.

Collectively these chapters and poems show there is much to be said about a place that too often is construed as a failure, a last resort, and a fate worse than death. In the course of working on the book together, we have had countless discussions with other colleagues and friends about their own experiences making decisions for family members with regards to long-term care. We consider this book part of a longer and bigger conversation, and we hope you will join us.

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