

Heather Carlile Carter and
Jennifer Carlile-Bortz

MAKING SPACE

Emotional and Practical Realities of Caregiving, Transitions, and Household Disbandment in the Older Adult Home

Aging Studies

Collection Editor
DAVID BETTS

LIVED PLACES
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To elders and those who care for them as they both make space
for breath and living amid this complexity.

Abstract

Making Space examines the emotional and practical realities families face as older adults move through caregiving, late-life housing transitions, and household disbandment or downsizing. Drawing on first-person narratives and qualitative research methodology, the book explores four thematic lenses: the emotional journeys caregivers navigate; the complications of strained family relationships; the transmission of legacy and inheritance; and the procedural orientations that help families move through daunting practical demands. The accounts span caregiver burden, cognitive decline and dementia, collecting and hoarding disorder, and the storied objects that convey meaning across intergenerational relationships. By revealing intensely personal, often isolating, experiences increasingly woven into the life of every family, the book reassures readers that they do not walk this path alone.

Beyond the family caregiver, this volume serves students, continuing education participants, and lifelong learners across gerontology, aging studies, social work, interior design, family studies, and counseling, with no prior academic background assumed. Undergraduate researchers will find humanizing context for empirical work on aging and caregiving. Faculty designing courses around the lived dimensions of late-life transitions will discover a course-ready resource anchored in authentic experience and narrative inquiry. Practitioners—among them geriatric care managers, social workers, health care providers, estate

professionals, and interior designers working with older adults, will gain a window into the lived experience of the families they serve and a resource for reflective practice and deeper client-facing understanding.

Individual narratives and sections are self-contained and can be read independently, making the book equally suited to small-group and community learning contexts, including caregiver support groups, faith communities, and book clubs.

Key words: gerontology and aging studies, informal caregiving and caregiver burden, cognitive decline and dementia, intergenerational relationships, late-life housing transitions, household disbandment and downsizing, legacy and inheritance, hoarding disorder and collecting, lived experience, narrative inquiry and qualitative research

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Content warning

This book contains explicit references to situations that may cause distress, including homelessness, drug and alcohol addiction, domestic abuse, child abuse, sexual abuse, violent assault, political violence, and murder. These topics do not arise in all narratives, but are integral to a few accounts told by the participants. As death and dying are central to the book's context, they recur throughout. Not all of these stories are easy, and readers are invited to move through them in whatever way serves their own well-being.

Preface

Informal caregiving for an aging family member or friend and the disbandment of their household have become defining moments in our middle adulthood. The literature surrounding these experiences skews almost entirely to the practical: pragmatic guides or quantitative research studies. What has largely been absent is literature oriented to the lived experience of the caregiver. This book seeks to address that gap.

Making Space exists because of a set of china dishes.

Heather Carlile-Carter is an interior design professor whose research focuses on material culture and the meanings people attach to the places they inhabit; Jennifer Carlile-Bortz is a writer and editor. They are sisters, and it was during the disbandment of their mother's household that this project began: Heather came upon a full set of her mother's china—acquired as wedding gifts and kept intact for decades, used two or three times a year. No one wanted it, and the void that lack created was not just a logistical problem, but an emotional one. The china had been cherished—it was no longer. Discarding it seemed somehow wrong.

As both a residential designer and a professor, Heather has spent years working inside and studying the homes of older adults and understands that designers are frequently present at the threshold of disbandment without any framework for the relational and emotional complexity waiting inside. The project was

initially conceived with that audience in mind, and its origins are still visible in the participant pool—a number of contributors are artists or design professionals. But as the interviews accumulated, it became clear that the experiences being described were not design problems. They were human ones, and the book belongs to a wider conversation about aging, caregiving, and the domestic life of older adults in America.

Making Space is not a clinical text, a prescriptive guide, or a representative sample. It is a collection of first-person narratives developed through in-depth interviews and illuminated with research. It will not tell you what to do; it will show you what others have done and what it cost them, situating experiences within the broader social, cultural, and psychological frameworks that help explain them.

The book is designed for multiple audiences and uses. Students in courses across aging studies, interior design, social work, gerontology, family studies, and counseling will find it accessible with no prior academic background assumed. Professionals—social workers, care managers, interior designers, health care providers, estate professionals—will find it useful as a continuing education resource and as a window into the lived experience of the families they serve. For small-group and community learning contexts, including caregiver support groups, faith communities, and book clubs, individual narratives and sections are self-contained and can be read independently.

The book's four sections—Emotional Journeys, Complicated Relationships, Legacy and Inheritance, and Navigating the Sort—were not designed in advance, but emerged from the

interviews, each lens taking shape as the dominant orientation of the narrative became clear. This provided distinct direction for supporting research, which includes a spectrum of work from seminal frameworks to more recent studies. Each section supports deeper engagement through learning objectives and discussion questions organized into personal, theoretical, and professional categories. Further activities provide structured opportunities for application, analysis, and reflection that can be completed outside the classroom without special resources. Each section also points readers toward a curated selection of memoirs that extend the conversation.

The narratives themselves were built through a process grounded in oral history methodology. Heather conducted all but one interview across multiple conversations. The interviews were open-ended and exploratory; her role was to follow the subject's account wherever it led. Jennifer shaped each transcript into a first-person narrative, working to preserve the subject's voice, cadence, and way of making sense of events. Each narrative went through iterative drafts that surfaced questions that required follow-up interviews. The final draft was returned to the subject for review, and any changes requested were incorporated before written consent and final approval were obtained. A few narratives were written by the narrators themselves or with Jennifer as a collaborator; those biographies note either "This narrative was written by the participant" or "This narrative was developed in collaboration with the book's authors."

What follows is not a complete picture of caregiving and disbandment in America. The authors sought a varied participant

pool, attending to socioeconomic, cultural, age, gender, and sexual diversity. These are stories routinely lived in private that turn out to be widely shared. If this book does what it is meant to do, readers will find in it not instruction, but company—and perhaps the recognition that what they are feeling or navigating, they are not navigating alone.

Acknowledgments

There would not have been a book without the people who agreed to participate in it. We learned from every participant. We are grateful for the trust you extended to us and for the honesty with which you shared your lives.

Participants gave us their time over many months: sitting for long interviews, reviewing drafts, answering follow-up questions, and revisiting experiences that were not always easy to name. Many spoke during periods of uncertainty and grief, when the work was still in process, yet they stayed the course. The interviews themselves became something more than conversations. Sometimes we teared up. Other times, we laughed. There is something remarkable about watching a person think aloud as understanding begins to take shape. At times it felt like witnessing ideas emerging in real time—vague at first, then clearer and more certain as words gathered around them.

To those participants who chose to write their own narratives, thank you for remaining authentic to your experiences and allowing them to exist on the page with candor and complexity.

We also want to acknowledge those whom we do not know but who are currently caregiving and disbanding. Much of your work happens quietly, behind closed doors, late at night, and without recognition. Some of it involves dirt, mold, and the physical realities of caring for a body that is no longer functioning as its owner wants. It is arduous and gut-wrenching. We know you are there,

and we honor the effort it takes to remain present for the people you love and for those you might not.

I, Heather, also want to acknowledge Jennifer's extraordinary skill as a writer and collaborator. When I asked her to pursue this project with me, she said "yes," even though she likely knew that wrangling me through the writing process would test her patience. It did. From the beginning, she put on a figurative hard hat, showed up to the writing construction site, and made the project happen. She was dedicated to each participant's voice while she created narratives from hours of interview transcripts. She spent over two years organizing, writing, editing, and pushing this book forward. Her spreadsheets were glorious. I treasured our Sunday work sessions—even when she responded to things I had done with indecorous emojis—and I admire her greatly and remain thankful for her partnership in bringing this book into being.

And I, Jennifer, could not leave Heather's dedication unspoken. Never has anyone had a more sincere cheerleader. As a writing partner, she matches me stride for stride, except for the occasional em-dash battle. As sisters go, she is as devoted as they come.

Finally, to those who believed there was a meaningful book within this idea and trusted us to pursue it, thank you for your confidence, encouragement, and support.

Introduction

Many families do not see it coming. Or if they do, they are not prepared for its impact. A parent's health shifts, a house becomes unmanageable, a crisis arrives—and suddenly adult children find themselves managing medical and logistical demands, navigating extended family, negotiating questions of autonomy. They are untrained. All of this occurs while they are absorbing the emotional impact of watching someone important to them lose pieces of their identity: strength, ways of thinking, lifestyle. The work of caregiving and disbandment often begins simultaneously. Neither experience announces itself with a name.

Household disbandment and caregiving are typically treated separately in practical and research literature, yet in lived experience, they routinely overlap. While sorting, moving, or dismantling tasks can intensify the burdens of care, caregiving decisions themselves may lead to changes in housing, possessions, routines, and family roles. This book documents that overlap.

Caregiving takes many forms; this book is concerned with its informal realm—the unpaid, mostly unacknowledged work performed by family members, friends, and others outside the professional care system. Informal caregivers are daughters and sons, spouses and grandchildren, neighbors who stepped in and never quite stepped out.

National data indicate that 38,200,000 Americans provided unpaid eldercare during 2023–2024 (US Bureau of Labor Statistics, 2025). Nearly half cared for a parent; many provided care several times a week or more, and caregiving commonly continued for years. Women continue to carry a disproportionate share of these duties in the United States, remaining central to the nation's caregiving infrastructure (US Bureau of Labor Statistics, 2025). Eldercare has become an increasingly common and long-term family responsibility across the nation. Broader demographic and economic trends, including population aging, workforce shortages, and rising long-term care costs, continue to place growing pressure on families to provide care within the home (Collyns, 2026). Research also shows that caregiving experiences are influenced by geographic and racial disparities. Rural caregivers and some racially marginalized groups almost always face greater barriers to health care services, financial stability, support services, and other resources while managing substantial caregiving tasks (Cohen, Nash and Greaney, 2024).

Unlike their formal counterparts, informal caregivers frequently enter the role with limited experience and no institutional support, scrambling to understand systems that professionals spend years training for. Boundaries are few. There is not a defined endpoint. Although caregiving is performed predominantly by women, this book includes men and nonbinary caregivers, too. They are all people who did not choose the work so much as find themselves inside it. The toll is considerable and well-documented: informal caregivers face elevated rates of stress, anxiety, depression, social isolation, deteriorating physical health, and financial strain (Rajan and Rajkumar, 2026). That is the norm,

not the exception. It is the condition under which every narrative in this book unfolds.

Although caregiving affects entire families, the work is primarily carried out by one person. That individual—often a daughter—absorbs the direct physical labor, the decision-making, the emotional management, and the anticipatory planning that surrounds it, while maintaining their own life. The load is seldom distributed evenly, and the person carrying most of it typically does so without a sense of when it will end. The work is viewed by the world at large as natural, as obvious, as something that simply gets done rather than something someone is doing at significant personal cost.

That individual cost radiates outward. Responsibilities routinely extend beyond the caregiver and care recipient to shape marital relationships. Research suggests that providing care to aging parents can influence marital satisfaction, while the caregiving process itself may alter communication patterns, intimacy, expectations, and everyday relationship dynamics as couples adapt to new roles (Brisini and Wang, 2026; Polenick et al., 2017). The demands of care can change daily routines, reduce time and energy for the relationship, and create new tensions around decision-making and responsibility, particularly when the older adult lives in the home. At the same time, couples who communicate openly about the caregiving experience seem better able to support one another and adapt together as circumstances change (Brisini and Wang, 2026).

Siblings who are not primary caregivers develop their own responses: guilt, distance, periodic intervention, disagreement

about decisions they did not have to make day to day. The question of who will take on the caregiving role—and the household disbandment—can itself become a source of conflict before the work has even begun.

Among the evolving demographics of caregiving, young adults remain a mostly overlooked population. Often, they are helping care for grandparents and other aging relatives while navigating higher education, early careers, and family formation. Yet many institutional resources remain poorly aligned with their circumstances. The Family and Medical Leave Act does not provide protected leave for many forms of extended-family care, and colleges, universities, and career-training programs have only begun to recognize the educational disruptions and competing demands that caregiving can create for young adults (Fingerman et al., 2025; Miller et al., 2024).

Dementia is present across many of these accounts—and it warrants naming directly. A 2025 study published in *Nature Medicine* found the lifetime risk of developing dementia after age 55 to be 42 per cent, with annual dementia cases in the United States projected to rise from approximately 514,000 in 2020 to nearly 1,000,000 by 2060 (Fang et al., 2025). Dementia introduces a particular kind of grief into caregiving. Families find themselves mourning someone who is still physically present, making decisions for a loved one who can no longer fully participate, and trying to sustain relationships that have fundamentally changed. Research suggests that dementia care is not experienced in only one way. Caregivers describe moments of love, connection, meaning, and reciprocity existing alongside fatigue, loneliness, uncertainty, grief, and emotional strain (Lindeza et al.,

2024). Studies further show that caregiving is not only a practical responsibility but also a relational process that can reshape identity, family dynamics, and a caregiver's understanding of loss and connection (Jeran et al., 2026).

Some forms of dementia can also change how people relate to their belongings, making it harder to sort, evaluate, or part with them, and adding another layer of complexity for families facing household disbandment (Mitchell et al., 2019). More broadly, attachment to possessions commonly increases in later life as objects become imbued with personal history and emotional meaning (Dozier and Ayers, 2021). What caregivers sometimes experience as resistance, stubbornness, or refusal may instead reflect a combination of emotional attachment, accumulated loss, cognitive change, and fear of further diminishment. Understanding this complexity helps shift household disbandment away from a simple process of "cleaning out" and toward a more compassionate view of what possessions can represent in later life.

Within a family, a home is put together over decades, and the household is layered with meaning. Disbandment takes that apart. It may be precipitated by a move to assisted living or memory care, by the death of an older adult, or by the gradual recognition that a home can no longer be safely maintained. It is related to, but distinct from, downsizing. Downsizing implies a voluntary and planned reduction made by someone still largely in control of their circumstances.

Disbandment typically involves less agency and greater urgency. It requires the sorting, distribution, donation, sale, and disposal of

almost everything a life has accumulated: furniture and clothing, photographs and records, objects of obvious value, and objects whose significance may be invisible to everyone except the person who kept them. It often requires family members to make difficult decisions together, sometimes on behalf of someone who can no longer make them independently.

As we think through household disbandment, much of its contemporary understanding builds upon the seminal work of sociologist and gerontologist David J. Ekerdt, whose research reframed later-life downsizing as far more than the practical reduction of belongings. His scholarship shows that the objects people live with over decades become intertwined with personal history, family relationships, routines, and identity, making relocation emotionally complex as well as physically demanding (Ekerdt and Baker, 2014; Ekerdt, Luborsky and Lysack, 2012). He describes household disbandment as the gradual dismantling of a long-established home during major life transitions such as illness, caregiving, widowhood, relocation, or declining independence. Decisions about what to keep, pass along, sell, donate, or release are driven by memory, responsibility, grief, affection, conflict, and reflection about what matters most. In later work, he further suggests that aging requires people to reconsider not how much they can preserve but which objects most reflect the lives that they have lived and the relationships they hope to sustain (Ekerdt, 2019). Together, his research helps illuminate household disbandment as an ongoing process of transition, meaning-making, and reshaping one's understanding of home. Aging in place—the widely shared preference of older adults to remain in their homes as long as possible—extends the timeline and emotional complexity of this labor.

With that, we need to frame hoarding. The word appears in several of these narratives, used by participants to describe what they encountered in a parent's or grandparent's household. In clinical terms, hoarding disorder is defined in the *DSM-5* (American Psychiatric Association, 2013) as persistent difficulty discarding possessions, regardless of their value, resulting in clutter that disrupts the use of living spaces and causes distress or impairment. Collecting, by contrast, involves organized, intentional, and targeted acquisition—selectivity is the distinction. What many participants in this book are describing, on reflection, is not hoarding disorder in the clinical sense, but accumulation taken to an extreme: decades of objects acquired with purpose and kept with care, overwhelming in volume but not without internal logic.

The vernacular matters because the word that a family uses gives direction to their response. To call something hoarding is to pathologize it, to position the older adult as a problem to be managed rather than a person who has an object-story worth hearing. Research on the families of those with hoarding disorder documents the strain it produces—damaged relationships, emotional triggering, ongoing conflict long after the physical work is done (Dewar et al., 2026). However, the line between disorder and accumulation is not always as clear in practice as clinical definitions suggest, and the book neither pathologizes accumulation nor sensationalizes it.

Another note on language follows from that. Readers will notice that the accounts use words like "stuff" and "things" where a more clinical treatment might reach for "material possessions" or "objects of significance." This is deliberate. The casual terms are

not imprecise; they are accurate to how most people talk about what fills their parents' houses, their garages, their basements. To impose clinical distance on language that is never clinical in lived experience would be a distortion.

The households in this book are full of belongings layered with accumulated meaning. Stacks of china never used. A grandfather's handwritten to-do list. A piece of furniture that crossed an ocean. When these objects are dispersed or discarded, what is lost is not merely a thing, but the tangible evidence of a family's existence across time. The disbandment of a household is a negotiation over what a family is willing to remember and what it can bear to release.

Stories operate the same way and sometimes more durably. Houses disappear. Objects are lost, donated, or discarded. But the stories attached to them—told across kitchen tables, repeated at funerals, passed from grandparent to grandchild in the particular language of a family—can survive when nothing else does. Family Caregiver Alliance, a national nonprofit organization that advocates for and supports informal caregivers, recognizes the power of story. It maintains a dedicated space where caregivers can share experiences and find solidarity with others in the same terrain. The narratives in this book draw upon that same power—accounts told in the participants' words, moved from voice to page and offered to readers who may recognize parts of their lives within them. They invite the reader to participate further, perhaps to tell their own story or to listen more carefully to another's.

Section 1
Emotional journeys

Learning objectives

After engaging with this section, the reader will:

1. Recognize intergenerational ambivalence as a defining condition of caregiving relationships rather than a sign of relational failure.
2. Connect the concept of liminality to the caregiver's suspended state between the role that organized their life and the identity not yet formed.
3. Reexamine their own assumption that conflicting emotions toward a family member must be resolved rather than held together.

Introduction

Caregivers' emotional journeys move unpredictably. Earlier family wounds may resurface during care, yet affection and connection frequently persist even within strained relationships, creating an emotionally ambivalent experience where conflicting feelings coexist.

Lüscher and Pillemer's (1998) framework of intergenerational ambivalence explains why caregiving relationships contain closeness and tension. These emotional contradictions can affect psychological and physical well-being (Fingerman et al., 2008), and positive and negative emotions do not cancel each other out (Gilligan et al., 2015). Mixed emotions are not just experienced by one person but can affect the entire family as everyone navigates new obligations (Reczek, 2016).

Caregiving can also rework identity and emotional understanding over time as people reevaluate their experiences (Kubitza et al., 2025). Loneliness, life satisfaction, and emotional well-being are impacted across the caregiving trajectory (Ping et al., 2025). Fernández-Carro et al. (2025) found that older adult caregivers experience negative and positive health outcomes, while López-Martínez et al. (2025) showed that caregivers who find meaning or satisfaction in the role may experience less long-term psychological distress.

The narratives that follow explore the ambivalent emotional journeys of five people who help us understand that caregiving is seldom defined by a single emotion. Although the caregiving aspects in these stories share the same intensity level for the participants, some journeys are of a longer term, adding greater cumulative stress to the life of the narrator. Across a spectrum from mostly positive relationships through enmeshment and intergenerational trauma, they are ordered by relational and historical accumulation over the narrator's lifespan.