THE
UPSIDE
TO AGING

Dear Family Caregiver,

No matter if you’ve planned to be the caregiver to your loved one or if you’ve happened upon the role quite unexpectedly, you’ve taken on the responsibility to care for your family member in one of the most vulnerable stages of their life. Navigating through this new chapter of both of your lives will no doubt have its challenges, but the opportunity to walk with your loved one through this new phase of their life is an honor and can be a valuable experience if you have the tools that you will need to succeed.

Family caregivers come from all walks of life, and yet the circumstances that many unexpectedly find themselves in are quite similar. Too often, family members are left to figure it out when it comes to addressing the physical, emotional, and social needs of their loved one. My mission in writing *Caregiving Both Ways* was to create a guide book for you that will aid you in navigating some of the more delicate aspects of care.

No daughter should have to live with a feeling of guilt of deciding to seek professional support to help care for her parent. Nor should they have to be left feeling hurt and confused if their parent no longer recognizes them. Yes, these aspects of care are real and they are deeply personal, but, if you are prepared for them and are given context for why it is happening, then you have the opportunity to understand and in turn provide support to your loved in these moments - in hopes to create lasting memories that you will remember.

Chapter One, released here, starts by acknowledging that you are not alone in the caregiving journey, and that family caregivers can be found in various roles and that while you may be alone in your journey with your loved one you are not alone in the caregiving community as a whole and that this experience is affecting so many people.

Caregiving Both Ways is available for purchase on August 15th and can be pre-ordered now at Amazon, Apple Books, Barnes & Noble, and INDIEBOUND.

Sincerely,

Molly Wisniewski

THE
UPSIDE
TO AGING

Caregiving Both Ways: A Guide to Caring for a Loved One with Dementia (And Yourself!

THE
UPSIDE
TO AGING

Table of Contents

Chapter One

The Unexpected Family Caregiver

The caregiver is often considered a hero. We acknowledge how difficult it is to care for someone else, and, while there are programs and support systems in place to advocate for the family caregiver, the bulk of the work is left to you to handle. The joyful moments spent with someone living with dementia or Alzheimer's are great, and I've had the honor of developing relationships with many individuals living with this disease. These moments, however, are formed outside the daily care routine. I've witnessed firsthand the struggles between caregivers and care recipients as they navigate the most delicate aspects of care. These intimate moments of caregiving hold a vulnerable part of the human experience, and one that should never be taken lightly.

The start of a caregiving journey will be different for everyone because the role of a caregiver can be brought on by an acute illness, or maybe you've assisted in a family member's care for years without realizing: a trip to the doctor's office, scheduling appointments, or light housekeeping. Often the tasks are easy enough, and for many people, these roles and responsibilities are taken on without much thought. As the family, many assume it is just part of what's required or expected.

Whether it is a spouse, a parent or sibling, grandparent, aunt, an uncle, or whoever raised you, they are older now and need a bit more assistance in their day-to-day activities. The process all seems innocent enough, but, as care demands increase, taking care of your loved one can unexpectedly begin to intrude on your daily routine, job, family, health, and finances. Without a proper plan in place, caregiving becomes a much more complicated process for family members to navigate.

While the word care may be in it, caregiving is practical and medically driven, which leaves very little time for emotional care and relationship building. Continued focus on a person's physical well-being can be both draining and stressful. As we move forward throughout this book, the acknowledgment of feelings of stress, guilt, and even anger is essential. So many caregivers have expressed these sentiments in whispered tones, as if they were wrong or something they should be ashamed for feeling. They are not.

These thoughts are healthy and come from being put in a difficult situation. What matters is the way you choose to handle these thoughts.

Due to the sensitive and delicate nature of providing care, it is essential that both parties agree to the care arrangements. The care recipient should express either verbally or in writing what kinds of care measures they agree to, who they want to be providing this care, and an agreement with that person that they are willing and able to take on the role. The caregiver should identify what kinds of care they can provide and understand in what aspects of care they will require additional assistance. Unfortunately, this is hardly ever the case. As mentioned above, family members take on the role unassumingly, and too often without a conversation with the older adult in need. Society tells you to plan for retirement, but the conversation often stops there and neglects to prepare for, or even discuss, a time when you are no longer able to care for yourself.

Longevity is a relatively new concept in our society. Black men who were born in 1950 had a life expectancy of fifty-nine; white men were expected to live to sixty-seven. Today, this is retirement age. Meanwhile, white women who were born in 1950 had a life expectancy of seventy-five; black women were expected to live to sixty-three.[1] Medical advancements and a better understanding and appreciation of nutrition and exercise have resulted in longer and healthier lives for both men and women. We never needed to make plans past retirement because no one expected even to live that long, so now, as we navigate the complexities of an aging population, planning becomes much more relevant and necessary.

To not have these conversations leaves family members to struggle to make the “right” decision for their loved one without knowing what they would want. For instance, AARP (American Association of Retired Persons) and the Centers for Disease Control report that 87 percent of adults over the age of sixty-five have expressed the desire to age in place (to live in one place through every stage of the aging process) [2,3]. However, to make aging in place a sustainable option takes a lot of planning and a lot of money. This, coupled with the less than ideal reputation of nursing homes and other senior care facilities, creates added pressure in deciding whether your loved one should come and live with you. I’ve had many conversations

---

[1] Senior Living, https://www.seniorliving.org/history/1900-2000-changes-life-expectancy-united-states/.

[2] AARP, *AARP Livable Communities* “Baby Boomer Facts on 50 Livable Communities and Aging in Place,” AARP, accessed April 1, 2019, https://www.aarp.org/livable-communities/info-2014/livable-communities-facts-and-figures.html.

[3] Centers for Disease Control and Prevention (CDC), *The State of Aging & Health in America 2013* (2013), accessed April 1, 2019, https://www.cdc.gov/aging/pdf/state-aging-health-in-america-2013.pdf

over the years with people who say “that is just what you do”; however, living with a parent or having the parent come live with you is a significant decision, and there are a lot of factors that should be considered before living together. Not everyone has a good relationship with their parents, but that doesn’t mean you won’t have to care for them. Don’t make the situation worse for yourselves by creating little to no space to step away from the caregiving situation.

The right care setting is out there for all of us; it just takes time and consideration. No doubt, if you have taken on the role of caregiver—no matter your relationship with your loved one—you want the best for them. Sometimes that means you are the primary caregiver, and sometimes it does not. If your loved one hasn’t made a decision on how they would like their care handled, or if they assume you are the person for the job without discussing it with you, you have every right to decide for yourself if this is what you want to do. You are not a bad person for saying that the emotional and physical toll of caregiving is just a bit too much for you to take on.

There are a variety of ways you can provide care for your loved one. Getting to know them during this new phase of their life is so important, and, when left to focus primarily on the physical care, this special time together can become muddled with stressful moments. You deserve to look back on this time with joy and love.

Accessing education or resources to learn how to provide care can be difficult. It’s not that there is a lack of information on the topic; rather, because caregiving is such a personal experience, it is hard to know where to start. But it is important that you know you are not alone. There are both experts and other family caregivers out there, advocating and educating based on their own experience, and they are more than happy to share what they have learned along the way to help you.

The Caregiver Generation

The role of the caregiver can be found in almost every generation, and, over time, our understanding and recognition of the caregiver’s role has been extended beyond the family. Over the past three generations, there has been a dramatic shift in the expectations of who gives care and the extent of the caregiving demands assumed by those individuals providing care. I started work in senior living in 2005 on a skilled nursing unit, and while I didn’t know it at the time, the demographic cohort I was providing care to was part of what many refer to as the Silent Generation. Born between 1925 and 1945, the Silent Generation are known for their "waste not, want not" mentality that many suggest they learned from living through the Great Depression. They are a population of fifty-five million in the US, and for the past twenty years had made up the majority of retirees.[4] They also gave birth to the Baby Boomers and, as they've gotten older, have been cared for by Boomers, who are an entirely different group of individuals.

The Baby Boomers were born between 1946 and 1964, and they are the largest generational cohort, making up 28 percent of the American population at seventy-six million people. Unlike their parents before them, the Boomers are known for their individualistic mindsets, are socially conscious, and make up the most substantial subset of the workforce. In 2011, the first wave of Boomers turned sixty-five, and it is projected that every day until 2030, ten thousand Baby Boomers will reach the age of retirement.[5] Over the fifteen years I've worked in senior living, I've watched as the Boomers started to move into long-term care and witnessed the challenges the field has already begun to face as others attempt to care for such a large subset of the population.

For now, many Boomers still provide care to their parents of the Silent Generation, and they are doing so as they plan for their own future care needs. One of the biggest questions we ask in the field is, who will take care of the Boomers when they need it? So far, many in this demographic have been vocal about not wanting the same kinds of care their parents had, and they are working to change the "face" of old age by challenging stereotypes. But, as a whole, this group is still not planning for their long-term care needs, and, if we as a society are to provide care to such a large group of people effectively, it is important that this generation join the conversation and take responsibility for making a plan for their future care needs.

As the number of people in need of care grows, there is a significant decline in available caregivers, and reports of nursing homes being short-staffed continue to increase. Simultaneously, the number of family caregivers has increased, and the National Alliance on Caregiving and AARP report that there are 43.5 million unpaid caregivers in the US and that this number will continue to rise.[6] At such high numbers, family caregivers, particularly those of the Baby Boomer generation, will be the most affected by the

---

[4] University of Missouri Extension, *Silent Generation / Traditionalists (born before 1946)*, n.d. http://extension.missouri.edu/extcouncil/documents/ecyl/meet-the-generations.pdf

[5] University of Missouri Extension, *Baby Boomers (born 1946–1964)*, n.d. http://extension.missouri.edu/extcouncil/documents/ecyl/meet-the-generations.pdf

[6] National Alliance for Caregiving and AARP Public Policy Institute, *Caregiver Profile: The Millennial Caregiver* (Washington, DC: National Alliance for Caregiving and AARP Public Policy Institute, 2015), 6.

burden of care. To become involved as someone's caregiver is a significant undertaking that involves a variety of factors, including your financial capability. Caregiving for an older adult is not a straightforward process, and there will be times when you have to handle vital decisions for the person in your care. To be put in this position without prior knowledge or understanding of the complexities of care is unfair and does not prepare you for the situations you will likely face along the way.

In this chapter, we take a closer look at the diversity of roles and settings that caregivers find themselves in, to shine light on the fact that caregivers take on many different roles, and, no matter what situation you find yourself in, you are never really alone in your journey. To recognize that people across our society are caregivers brings much-needed awareness of the support and flexibility we should be providing this growing subset of our population. As you move through this book, consider what kinds of care you feel comfortable with and able to provide your loved one.

Caregivers in the Home

There are family members who are willing and able to take in their loved ones who are living with dementia or may no longer be able to live independently. The multigenerational home (grandparents, parents, and children living in the same household) is a growing trend in our society. Pew Research estimates that sixty-four million people live in multigenerational homes, and this number will continue to rise as children move back home after college to save money and older adults move in to save on expenses or seek care.[7]

There are many benefits to living together and, while there are challenges, many such caregivers feel reassured that, if anything were to happen, they would be right there to help. There is more time to get to know and support your loved one during this new phase of their life. Coming together for mealtimes or spending quality time watching a movie or playing a game creates lasting memories you can look back on and cherish.

---

[7] D'vera Cohn and Jeffrey S. Passel, "A record 64 million Americans live in multigenerational households," Pew Research Center, April 5, 2018, accessed April 1, 2019, http://www.pewresearch.org/fact-tank/2018/04/05/a-record-64-million-americans-live-in-multigenerational-households/.

It is also easier to establish and maintain a caregiving routine when you live together. Particularly when you care for someone living with Alzheimer's disease or dementia, following a routine will aid in making each task a bit smoother. Living together can even help save the family money if your loved one is willing and able to contribute to the household. However, while it may sound economically savvy to invite your loved one to live with you, the decision shouldn't be made lightly.

The traditional single-family home was designed for the thirty-something family, which means it is ill-equipped to support the needs of an older adult. Smaller doorways, two-story homes, tubs, and even doorknobs can become obstacles for older adults who have mobility issues or arthritis. When a family caregiver invites a loved one to live with them, they will most likely need to consider renovations and home safety modifications throughout the home. For some, the financial undertaking to make these changes may not be an issue, and, in fact, these kinds of universal design features will allow the family to grow in the home, too. But the economics of it all should be considered, as these elements will cost money and raise the question of who will pay for them.

Caregivers in the home also have little to no separation from their caregiving duties. Because they are in such close proximity, they become the default person for almost every situation, which in theory makes sense. Many times, I've heard caregivers express that they would rather be right there if something should happen; however, caregiving involves more than just emergency situations. If your loved one wakes up twenty times throughout the night to go to the bathroom and gets lost on the way back to their bedroom and becomes anxious and fearful, you are the person that will be getting up with them to take them back to their room and soothe their anxiety every time. You also will have to get up the next day and be able to function properly and be productive at your day job as if you hadn't just spent the night tired and anxious yourself.

It is in these raw caregiving moments that light needs to be shined on the fact that caregiving in the home is a 24/7 job. It can be traumatizing to watch your parent or loved one forget where the bathroom is, struggle to remember who you are while they are living under your roof, or yell at you for not helping them when that is all you are trying to do. It becomes so difficult to separate the parent from the diagnosis, and it is an unfair situation for any family member to have to face.

Yes, cohabiting can be the ideal situation for some families and, after a thoughtful conversation on boundaries and expectations, it most certainly can be beneficial. However, the decision to have your loved one move in with you may not be the best one simply because it makes the most economic or logistical sense or because it is the “right” thing to do. I urge you to take time to consider your options and your ability to be a caregiver at all times, throughout the day and night. Take comfort in knowing it’s okay to decide that co-living is not the best choice for you, your loved one, and your family.

Caregivers with a Loved One in a Nursing Home

Caregivers with a loved one living in a nursing home have a vital role in the care and well-being of their loved one. They may not realize it, but their presence ensures the safety of their loved one and ensures that the care that they are receiving is not the only thing they have to look forward to. They can count on you as a familiar face to remind them that they are more than their care needs—that they are still able to live a life beyond the assistance of daily living they receive from their caregivers. This break from the constant medical focus is a breath of fresh air for so many individuals who have no other choice than to move into a care home.

A person’s ability to engage with their loved ones while in the care of professionals is essential to their quality of life and their well-being. Residents who do not have any visitors struggle to find companionship while living in a nursing home. Yes, there are people there every day to take care of them, but they are paid. While they are willing and may even create bonds with these individuals, they are there to fulfill their duties and, if they have to leave, will do so despite these bonds. Family members play a significant role in the safety and well-being of their loved ones living in a nursing home; they are still needed and are still caregivers, even if the care recipient is living in a nursing home. Too many family members entrust companionship to the caregivers they or their loved ones are paying to take care of them. It is possible that the sight of their loved one in need of such skilled care is just too much to handle for some, and they may stop coming altogether. But they need you now more than ever.

Transitioning into a care home is a new chapter in someone’s life, but that does not have to mean it is the last. A lot of learning happens in these settings. People learn how they handle giving up control of many of their normal functions, and they entrust those around them to provide for them in a way that they have spent most of their life doing on their own. For family members, it is hard to see this, to look past the glaring realities of your loved one's health or even cognitive decline. They will change reasonably quickly while they are here, but that doesn't mean you shouldn't be able to try to get to know them as they maneuver through this process. You are and always will be an important part of their lives, and to not be there during this frightening period can cause profound regret as the loved one passes away. You are their family first, and you deserve the chance to embrace this role and to help guide them through this new phase.

The Long-Distance Caregiver

A long-distance caregiver is someone who lives at least an hour away from the person in need of care—someone who is not able to pop over at a moment's notice and often needs coordination to make a trip over to the individual's home. Generally, long-distance caregivers are not the primary caregiver, and will often act as the support to the family member living closer to the care recipient. It is challenging for someone who lives far away to know how they can meaningfully engage in their loved one's care, but there are ways to play a significant role even if it means that you are a just a little bit more hands-off in your approach.

If you are a long-distance caregiver, knowing how you can help and where you should start in the caregiving process can be difficult. Start by having a conversation with your loved one and their primary caregiver (if this is someone other than you). They will both have a better sense of how you can be most helpful and this will prevent you jumping into, and perhaps disrupting, an already well-established process.

A long-distance caregiver has an excellent opportunity to be much-needed support for the primary caregiver in their loved one's life. The daily tasks of caregiving are draining, so taking the administrative to-dos from their list can sometimes save them both time and energy that they can refocus on themselves or the care recipient. The times when you do come into town can provide respite breaks for the primary caregiver, and you should include them in your plans for your trip home so they can schedule their time accordingly.

Researching and knowing the resources in your loved one's community is another great way to support them from afar. You may not be able to ensure they are exercising daily, but you can work to coordinate their attendance at their local senior center in hopes they exercise there! Checking out their local Area Agency on Aging is a great place to start in your community resource search—the AoA no doubt has already done most of the research and can point you in the right direction if you are looking for something specific for your loved one.

There is a lot of support and help that a long-distance caregiver can provide without physically being with their loved one. Technology has done a great deal to expand the role of the long-distance caregiver, too. For example, my next-door neighbor grocery-shops for her mom who lives out West and has the groceries delivered to her front door, so her mom doesn't have to worry about going on her own. Online bill pay is another way long-distance caregivers can use technology to support their loved one.

In addition to the practical support that technology can help you provide, opportunities for emotional connection and relationship-building have increased as well. For instance, platforms like Skype or Facetime are fun ways to connect and interact with them that allow them to see you as you talk. You can also send home movies of yourself and your family that will help keep them engaged and present in your life with them. If your loved one has Alzheimer's disease or other forms of dementia, you can create videos or a playlist of their favorite sing-along songs. Finding ways to engage with them through technology is a close alternative to being there in person when you live too far away to visit.

Caregivers in the Workplace

I have worked in a variety of settings, but I always seem to encounter a coworker who is also a family caregiver. When I tell them my focus in the aging field, our conversations can quickly become personal. These deeply personal stories of caregiving are becoming more frequent in the workplace. And for these workers, strain from outside stressors undoubtedly has an impact on their productivity and performance. AARP reports that 61 percent of family caregivers are currently employed either full-time or part-time.[8] Since this number will only increase in the coming years, this issue demands attention.

---

[8] Lynn Feinberg and Rita Choula, "Understanding the Impact of Family Caregiving on Work," Fact Sheet 271, AARP Public Policy Institute, October 2012, accessed April 1, 2019,

For instance, one past coworker, although she made a decent living wage, was concerned that her parents, who never saved for retirement, would be retiring just as her second daughter started college. Since she was responsible for paying for both, she half-humorously joked that she had come to realize she will never be able to afford to retire. Another example happened on the way to lunch the other day. I walked by a woman noticeably upset at the sudden aphasia (a language disorder that affects a person's speech) her father was experiencing after a recent stroke. She expressed frustration at her inability to understand him, sadness that her father was ill, and exhaustion that now, on top of preparing her kids for a new school year, she would be spending the next few months searching for care facilities. In both cases, and the countless others I have encountered, there is a noticeable trend. As they are speaking, a look of disbelief is in their eyes, a shocked tone is in their voice, and a declarative "I don't know how I'm going to do it" is said at the end of each story.

Advocates for caregivers push companies to realize the importance of understanding and planning for a workforce made up of family caregivers. And for a good reason: without flexibility and understanding from businesses, caregivers are faced with having to leave the workforce altogether to support the needs of the older adult in their life. Early retirement then puts a strain on their ability to afford their own future care needs.

What Can Employers Do?

First, companies need to accept that this is a workplace issue. They will find that there is a range of policies and programs they can adopt to better support their workforce.

Hold a meeting. You may already have a weekly meeting on the calendar. Take five minutes to announce interest in this initiative, and possibly even to survey how many of the employees are in fact caregivers.

---

http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf.

Collect and distribute caregiving resources. AARP is a national leader in advocating for caregivers. Their program ReACT is an online resource designed for the workplace which acquaints employers with best practices to support their workforce and maintain productivity.[9]

Start a workgroup. Opportunities for employees to meet and discuss shared experiences can do wonders for their mental health. Although this meeting could be held before or after business hours, holding it during office hours ensures that all employees can attend if they want to.

Consider telework and compensatory time. The typical nine-to-five workday is confining and offers little opportunity to schedule medical appointments for our loved ones without having to take time off work. Teleworking and comp time provide flexibility and allow employees to attend appointments while maintaining productivity.

Investing in staff creates a friendlier and more productive workforce. There are a staggering number of caregivers with full-time and part-time jobs, and the number will only increase over the next few years. Employers have an opportunity to not only foster a healthy work environment within their company, but also provide a better quality of life for their employees and, in turn, the older adults who depend on them every day.

The Sandwich Generation

An individual considered part of the Sandwich Generation has a parent over sixty-five and a child under eighteen or a grown child still in need of parental support. Pew Research found that 71 percent are aged forty to fifty-nine and are providing care at both ends of the spectrum at the same time. For many years, Baby Boomers made up the bulk of the Sandwich Generation; however, as Baby Boomers continue to age, they are now being cared for by the next generation of the Sandwiched—Gen X who were born between 1965 and 1979 and are currently between thirty-nine and fifty-three years old.[10]

---

[9] Respect a Caregiver's Time Coalition (ReACT) and AARP, *Supporting Working Caregivers: Case Studies of Promising Practices,* Respect a Caregiver's Time Coalition (ReACT) and AARP, June 2017, accessed April 1, 2019, http://respectcaregivers.org/wp-content/uploads/2017/05/AARP-ReAct-MASTER-web.pdf.

[10] Kim Parker and Eileen Patten, *The Sandwich Generation Rising Financial Burdens for Middle-Aged Americans* (Washington, DC: Pew Research Center Social and Demographic Trends, 2013).

The Sandwich Generation makes up the bulk of our workforce, and, while more affluent households ($100,000 a year or more) are more likely to provide this type of care, the Sandwich phenomenon does not discriminate. This generation reports providing care, financial support, and emotional support to both their children and their parents simultaneously. A majority also feel just as obligated to provide for their aging parents during this phase of their life as they do to provide for their children.[11]

Becoming a caregiver to both parents and children in midlife offers a unique perspective on the spectrum of life. Some caregivers find it humbling and a great honor to be able to provide this kind of love and support to their family. This is a beautiful sentiment that is unique in the caregiving experience, as many of these individuals will learn how to provide care on a variety of levels. However, the financial burden of providing for both children and parents is great, especially as caregivers try to save for retirement. On average, the Sandwich Generation will spend seven thousand dollars in out-of-pocket caregiving costs.[12]

The Millennial Caregiver

I am a Millennial. I am right on the cusp of the generational shift, and, over the past couple of years, I've noticed a distinct change in the conversations I have with others in my cohort. While we discuss near-future decisions like careers, homes, and starting a family, the question of how close to home we should stay becomes a critical factor in the decision-making process. Why wouldn't it? The comforts of home are attractive to many of us, especially as we get a bit older and feel more inclined to carry on family traditions. Being closer to home also helps if and when close family members start to need additional care or support.

The National Alliance for Caregiving and AARP Public Policy Institute's report on the Millennial Caregivers says the average age of this cohort's caregiver is twenty-seven. They are working full-time, half of them live with a spouse or partner, and on average they have graduated high school and taken some college courses. All live with or live close to the care recipient.[13]

---

[11] Ibid.

[12] Jody Gasfriend, "Survival for the Sandwich Generation: Navigating the Hidden Costs for Working Caregivers," *Salon*, May 21, 2018, accessed April 1, 2019, https://www.salon.com/2018/05/20/surviving-the-sandwich-generation-navigating-hidden-costs-for-the-working-caregiver/.

[13] National Alliance for Caregiving and AARP Public Policy Institute, "Caregiving in the U.S. 2015," June 2015, accessed April 1, 2019, https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.

For those who aren't yet caregivers, the chances of becoming one are incredibly high due to the number of older adults who will be in need of care over the next twenty years. An increased generational focus on higher education and career means that many in the Millennial cohort will start a family and buy a home much later than their parents did. A later start means they will be in full-blown parenting and career mode when their parents begin to need additional care. Many of them are already privy to the realities of the family caregiver role. Their parents are Baby Boomers who have had the wild experience of raising a new generation while caring for the one that came before them. They are now left with the question, "Who's going to take care of me?"

The Caregiver for the Caregiver

Many caregivers are so busy taking care of their parent or loved one that they have either forgotten to or chosen not to take care of themselves, leaving their spouses, children, other family members, and even friends to step up and help take care of the caregiver's needs.

While this attention may not be as physically demanding as what the caregiver is providing for the older adult, these assistants to the caregiver work in several other ways. They provide emotional support and will spend most of their time listening and allowing the caregiver a safe space to vent. They assist in researching resources and support networks in the community. They understand their time with the person will change due to the scheduling constraints that accompany caregiving demands.

The assistant to the caregiver will most likely see it all and provide the bulk of the emotional support without receiving much reciprocation. Caregivers will spend all their time and energy on their loved one's care so that, too often, they have little left to give to other loved ones in their lives. It can be challenging to strike a balance when in the throes of caregiving, but the support you are providing them does not go unnoticed.

It Takes a Village

Caregivers are our neighbors, our coworkers, our friends, and our families. They carry on each day with the needs of their families and their loved ones on their minds. Caregivers are a part of the fabric of our society, which is essential to acknowledge for two reasons: 1) You, the caregiver, have representation and validation that you are not alone in this journey, and 2) our society sees the needs of our caregivers and can provide them with structural support. Caregiving needs are wide-ranging and rapidly changing today, and government agencies, businesses, non-profit organizations, and community members not only recognize these needs and changes but also are in the process of changing the way they do business and offering a host of resources and services for our care recipients.

I heard a recent news story about a small-town family whose son uses a wheelchair. Their community park installed a wheelchair-accessible swing, and the mom made a comment that resonated. She said it had been mainly up to the family to make the world available for her son, which meant everything from walking/wheeling down the street to recreational pursuits so her son could have a fun childhood. An image of her son and the rest of the family laughing and smiling around the swing set spoke strongly of the joy that this intervention had brought to this family. Because this community chose to install an accessible swing, this mother didn't have to explain to her son why he couldn't play in the park like all the other kids. She didn't have to figure out another way to have fun outdoors with her family. Because the town took the initiative to provide the structural support, she didn't have to adapt and could enjoy a playful moment with her son.

While this example speaks to the needs of a younger generation, I believe the situation is the same for older adults as well. Our communities and businesses have an excellent opportunity to design for the needs of older adults because, when you plan for them, you benefit everyone in the community. Efficiently designing for older adults requires design thinking because it is crucial that thought, empathy, and emotion are incorporated into the design. An efficient design will allow an older adult to continue to age independently and help them feel safe and secure in their surroundings.

Making the transition to an age-friendly community can be a process. However, there are relatively small-scale design features a city can implement to get the innovation process started. Like the accessible wheelchair swing, brightly painted crosswalks, wheelchair access on every street corner, and handrails along walkways are just minor changes communities can make to keep older adults and their caregivers active in their community. Caregivers, too, can play an active role in the shift in design for our communities. If your loved one needs a wheelchair ramp on their street corner, then consider calling your neighborhood associations or advocating on their behalf at your local town hall meetings. Notifying community organizations, businesses, government, etc. of the specific needs is the fastest way to see changes.

Over the past fifteen years I've witnessed a shift in this direction—a shift that recognizes the needs of caregivers and offers support to help you provide the best care to older adults. There are resources and people out there advocating on your behalf and I am encouraged by the progress, but we aren't all the way there yet. Not all communities offer fair pricing for adult day services or respite care, and we haven't really talked about caregiving on a personal one-on-one level. There are ways to maintain other relationships while caregiving, and it is okay to say you can't provide care today.

As an activities professional, I worked with individuals living with Alzheimer's disease or other forms of dementia on a daily basis. I had to learn non-medical ways to intervene for each when they started to become upset or anxious. Designing a caregiving plan that would benefit the individual while reducing my stress and worry about them was essential to my ability to provide a good quality of care and a good quality of life to each resident. Over time, I learned what worked and what didn't work, and I soon had many tools in my "arsenal" for each resident I worked with. These tools are what you, the family caregiver, are left to figure out on your own; as you play many different roles, like nurse, aide, dietitian, and transportation and recreation provider, it is nearly impossible to create a cohesive caregiving plan.

You are caring for someone you've known for some time; they know you and trust you. You have memories with them that have created a foundation for the caregiving process. But your relationship with them shouldn't have to take the back seat. Activities provide a fantastic opportunity to refocus your attention on the relationship with your loved one, and thus make the caregiving experience more manageable and less stressful. As you continue on your caregiving journey, it is important to recognize that you are not alone, and that there are resources and connections available to ensure that you are able to provide the best quality of care to your loved one. Don't be afraid to explore your boundaries and decide for yourself what type of care you can provide on your own, and where you may need additional support.

. . .

Caregiving Both Ways is available for purchase on August 15th and can be pre-ordered now at Amazon, Apple Books, Barnes & Noble, and INDIEBOUND.

Pre-order on Amazon.com today https://amzn.to/2VF8Zwb

Pre-order on Barnes & Noble today https://bit.ly/2LGweQw

Pre-order on INDIEBOUND today https://www.indiebound.org/book/9781633539846