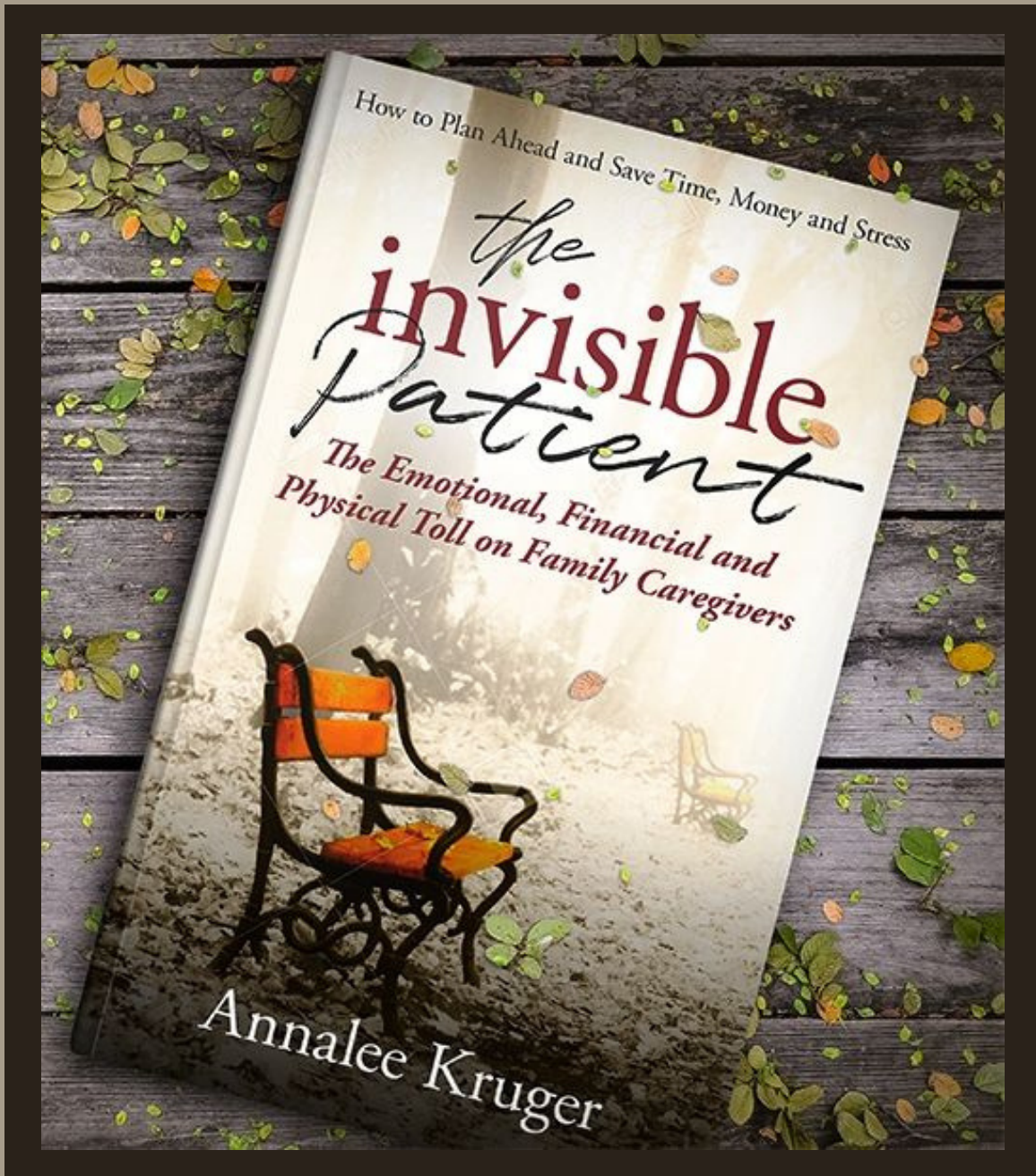


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The Invisible Patient: The Emotional, Financial, and Physical Toll on Family

Caregivers: How to Plan Ahead and Save Time, Money, and Stress—Annalee Kruger. -- 1st ed. ISBN: 9798465821285

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Impact of Caregiving

It is unrealistic to expect one person to be the caregiver to a loved one 24 hours a day, seven days a week. Relying on one person to provide all those needs will result in caregiver burnout. In the article, Family Caregivers of People with Dementia, published by the U.S. National Library of Medicine, authors Henry Brodaty and Marika Donkin note, "Family caregivers of people with dementia, often called the invisible second patients, are critical to the quality of life of the care recipients. The effects of being a family caregiver, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardship. Caregivers vulnerable to adverse effects can be identified, including factors that alleviate or exacerbate burden and strain. Psychosocial interventions have been demonstrated to reduce caregiver burden and depression and delay skilled nursing facility/center admission. Comprehensive management of the patient with dementia includes building a partnership between health professionals and family caregivers, referral to Alzheimer's Associations, and psychosocial interventions where indicated."

Spousal Caregivers

The seventy to ninety-year-old senior population takes their wedding vows seriously. Many spouses feel guilty if they need someone to come in to help take care of their spouse. They take the portion of their wedding vows, "'til death do us part," quite seriously and are determined to take care of each other. Eventually, there comes a time where it is just not healthy and safe for someone to remain at home. Or it may be unsafe for the spouse to take care of their loved one due to their physical limitations.

Often the spousal caregiver just needs to be reassured that they are still caregivers even when requesting help. When they move their loved one into an assisted living community, a memory care unit, or a long-term care unit, that spouse feels incredibly guilty because she feels like she is letting down her spouse. Spousal caregivers need a lot of permission, support, validation, and education.

Another issue within that generation is that they have never slept or been apart. The couple has done everything together. As a result, there are many adjustments that the remaining spouse at home must make. For example, if the wife always did the cooking, cleaning, and laundry, but her mental decline dictates she must go into an Alzheimer's or long-term care facility. The husband, still at home, may have never run the washing machine or dishwasher and doesn't know how to cook. Those role changes can be overwhelming and devastating for the spouse at home to figure out. Or, if it is a husband that always took care of the bills, finances, and investments and must go into a facility, the wife may not know how to pay bills or manage investments.

Changing roles from a spouse to a caregiver often causes resentment. Some spouses complain that the caretaking role isn't the retirement that they envisioned. At some point after retirement, their loved one experiences a stroke or some other disorder. As a result, they are now basically homebound, unable to travel or do what they hoped to do during their retirement years. Tasks like changing an adult diaper or becoming a chauffeur because the spouse can't drive any longer often cause strain within the marriage. One spouse is trying to maintain self-dignity while the other is trying to provide personal care.

Adult Child Caregivers

Another difficult role reversal is the adult child caring for a parent. For example, it is uncomfortable if the daughter's dad needs help with toileting or showering. It is the same scenario with sons and their mothers who require personal care. Relationships can get strained not only for personality difficulties but also because of dignity issues. Children may have seen their dad as the decision-maker in the house

or their mom as the go-to person when they needed a confidant about their troubles. When the parents get older or dementia sets in, roles change because the relationship changes. These role changes can be challenging for families to accept as new situations or developments occur.

The work-life balance for adult children is one of the most complex issues to deal with because as her loved ones get older and needs increase, someone has to be there to take care of those needs. However, the adult child caretaker may also be caring for small children or grandchildren and need to attend events or school functions while still employed.

Nearly all the daughters who seek Care Right Aging Plan and consulting services are utterly burned out. They may be the primary caregiver to multiple aging loved ones like parents, step-parents, in-laws, or an aunt or uncle who never married or outlived their kids. I always say, "Caregiving isn't like Thanksgiving; there isn't always room for one more!"

Caregiver Isolation

Caregiver isolation is a huge problem commonly occurring in two categories: familial caregiving (a spouse, adult child, relative of loved one) and caregiving of those with debilitating prognoses who require significantly increasing care as time passes. As the need for caregiving increases, the caregiver's risk of isolation, anxiety, and depression increases. The more care someone needs, the more attentive and physically present a caregiver needs to be. Many caregivers report not attending regular activities (book club or Bible study, for example) for weeks or months because they can't leave their loved ones home alone. Or, they don't participate in activities because they feel guilty that they want to attend the activity but cannot lift the loved one's wheelchair or walker into the car. As a result, they are not participating in errands, tasks, or other activities that used to be simple to do.

Caregiving for a loved one with dementia is incredibly stressful. As dementia progresses, there are definitely changes in that person's mood, behavior, and personality. The loved one may exhibit different or unusual behaviors to which her family and friends are not accustomed. For example, the dependent may be experiencing some episodes of paranoia where she thinks people are stealing from her, or she may just be easily annoyed and angered. The loved one might display bouts of tearfulness, become incredibly restless, begin to wander, pace, or may express inappropriate sexual behaviors. Those kinds of behaviors make it difficult for visitors to know how to respond. Because the loved one can exhibit these behaviors at any time, for example, while visiting a friend's house or going to restaurants or church, caregivers will withdraw from these types of activities, increasing their isolation.

The potential for isolation holds, as well, if taking care of someone with Parkinson's, Lou Gehrig's disease (ALS), multiple sclerosis (MS), or any progressive disease. The caregiver's ability to run quick errands is made almost impossible by the need to deal with wheelchairs, walkers, or electric scooters. By the time she situates the loved one into his wheelchair, gets the wheelchair to the garage, and is loaded into the car, it has taken a great deal of time and energy, making it easier to rationalize not needing to get out of the house.

Risk of Caregiver Injury

When taking care of a spouse with dementia, the one with dementia may have the physical ability. In contrast, the other spouse has the mental capacity to pay bills, and doctor appointments are kept. Between the two of them, they are a functioning unit. However, if the couple is elderly, the caregiver's spouse may also have health conditions and frailty. If she is the caregiver to her spouse, she could easily be injured while performing caregiving duties. For example, if her husband is prone to falls, she is at risk of falling, as well, if walking with him, or both falling if she tries to help in the shower. Sometimes, persons with dementia become combative, potentially causing more injury to the caregiver.

Transportation Issues

Another challenge associated with caring for elderly family members is difficulty transporting the loved one to doctor's appointments. More families are starting to use Uber or senior taxis if their loved one is not disabled. However, it can be tricky if the caregiver must manage wheelchairs or walkers. The downside of using these companies is they just drop the senior off at the curb. They do not ensure that the senior gets inside the building and through the check-in process.

In rural areas, transportation is a much bigger issue. If the loved one or family practices a faith, a temporary solution might be asking someone from church willing to take the senior where they want or need to go. However, if wheelchairs or walkers are involved, or if the senior is a high fall risk or has dementia, volunteers don't want moral or legal responsibility associated with potential injury or wandering away. This situation makes friends and neighbors less agreeable to take seniors to the grocery store or run errands.

Time Constraints

If the caregiver is on her own in providing transportation, she is often exhausted, frustrated, or annoyed when she gets to her destination. If the caregiver is the adult child and still in the workforce, she uses vacation days or unpaid time for appointments, which may take an entire day. Extra time is needed to transport the senior, wait in doctor's offices, pick up prescriptions, return the senior home, and return to the caretaker's home. The caregiver needs physical resilience, patience, and the necessary time to accomplish all tasks.

Each appointment can take a full day, with two to three appointments per week. Caregiving becomes a full-time job that snowballs as the loved one's condition deteriorates. The caretaking tasks start small, like getting mail or helping with laundry. Suddenly, you are using all your vacation days and feeling overwhelmed, frustrated, resentful, and isolated.

That is why I call caregivers the invisible patient. They are actively working to ensure that the person for whom they are responsible has all needs met. However, in doing that, they tend to neglect their own needs, like social, marital, spiritual, emotional, physical, or job and career advancement opportunities. Caregivers frequently jeopardize their health, finances, relationships, and wellness.

Elders Who Resist Care

Many older adults will claim they are doing simply fine on their own. However, when you go into their home, it smells of urine with stains on the carpet or toilet, and they are eating spoiled or expired food items. Or, they are bruised from falls, have lost weight, present with poor hygiene, and have an unkept home. These are clear indicators that assistance is needed. Understandably, the senior desires to preserve their pride and dignity even when things are not going well.

This mindset makes having these types of conversations difficult. Families who have tried to discuss issues independently find the discussion does not go well. When the adult children discuss caretaking issues, they get pushback and resistance from their aging loved ones. This must be handled as delicately as possible, often by a neutral third party.