Caring for Aging Parents

Straight answers that help you serve their needs without ignoring your own

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Introduction

Honor your father and your mother, so that you may live long in the land the Lord your God is giving you. Exodus 20:12

God places high value on the parent-child relationship. He Himself specifies in the Fourth Commandment that we are to honor our parents. In working out this honor, we sometimes find turmoil. What exactly does this word honor mean in today's world? What must we do to honor our parents? More to the point, how can we honor them without dishonoring ourselves or our own families?

No other relationship in your life has this kind of history. Your parents are the giants who ruled your family of origin; from them you learned your initial, and lasting, meaning of what it means to love. They are the people who served as your counterpoint during your stormy adolescent years. They are the pillars of culture who shaped you into who you are, who provided the discipline that you craved and despised. Here are the people whom you held in contempt

at times while still loving them and seeking their approval.

There comes a point in your life when these important people—who have provided support and love for you—need your support and care. Roles change and responsibilities change. Where once you needed them, they now need you.

Few human endeavors offer more opportunity for spiritual growth and development than elder caregiving. This miraculous opportunity for personal spiritual growth can be an emotional tangle of frustration, hopelessness, and guilt. You can avoid that tangle by equipping yourself with knowledge of successful caregiving and aging, finding support for your efforts, and finally, depending on the help of God's Holy Spirit to inject your faith into the caregiving role.

In this book you will explore a technique I call "Christian Personality Powering" and find how to apply it to the elder caregiving relationship. Elder caregiving is a unique calling to serve God's children in a special way. You will depend on Christ's presence in your daily life. It is in serving that you grow. Yet you are called to honor, not to give yourself away.

The Need for Care Is Expanding

The medical community works overtime to keep bodies alive—and it's succeeding. However, few mech-

anisms in our culture help family caregivers shoulder the sometimes awesome burden of care required by individuals whose lives have been extended through "medical miracles." The growing number of frail elders in our society is unprecedented in any culture and represents a grand experiment never before undertaken. The outcome of this medical and societal experiment is unknown at this juncture.

One result of this medical success is that family caregivers can buckle emotionally under the burden. I work in a large medical center where I routinely hear well-meaning, but sometimes emotionally insensitive, doctors blythly say to the family caregiver at the time of her parent's discharge, "Of course your mom will need 24-hour care for the foreseeable future."

This shock penetrates the caregiver like a driven spike. ***How can I possibly do that? Who can help me? What will I do—I have a full-time job!*** Fear cascades over the woman who has, without ever volunteering, just entered the ranks of the army of adult child elder caregivers. Her life will never be the same! Without the benefit of an orientation session, let alone any formal training, she awkwardly gathers herself up and heads into the great caregiving unknown. At this fragile point she has not a clue about the breadth and depth of the dramatic life challenge she faces.

A Few Final Notes before You Continue

I will often use feminine pronouns to refer to both aging parents and adult child caregivers. While both categories obviously contain members of both genders, statistics tell us that the average woman will spend more time caring for her parents than raising her children. Demographics indicate that women live longer than men.

Throughout the book, I refer to ***elder caregivers.*** The term ***elder caregiver*** does not refer to an old caregiver but rather to any person—usually an adult child or spouse—who either directly or indirectly gives care and support to an older person. I like to refer to older persons as ***elders*** or ***seniors***; these terms are more dignified than the commonly used term ***elderly***, which I believe to be patronizing.

One doesn't need to give direct care to be a caregiver. Adult children who live in cities far distant from their aging parents can still be caregivers. They take this role if they ***care*** deeply about the welfare of their parents and expend time, money, and other emotional resources in support of their parents. Anyone who has an older parent or who "cares about" any older person is a caregiver. It is to these sometimes burdened, and many times unappreciated, persons that I dedicate this book.

Richard P. Johnson, Ph.D.

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The Strain of Care

Now my heart is troubled, and what shall I say? "Father, save me from this hour"? No, it was for this very reason I came to this hour. John 12:27

It happened again! As she pulled away from her mother's apartment complex, Carolyn gripped the steering wheel so hard her knuckles turned white. Why was it that each visit to her mother became a struggle with quiet tension, internal disappointment, and repressed frustration—all converging to undermine her intense desire to have a close, heartfelt relationship with her mom?

Carolyn's mother, now age 82, suffers from several chronic ailments, including osteoarthritis, hypertension, and intermittent angina. Carolyn is the second oldest of five children. Her older brother, Ted,

lives in a distant city. Even though he seems concerned about his mother, he can't give much direct care to her. Her two younger sisters and one brother seem too consumed in their own worlds of family and work to take any active role in their mom's care. This leaves Carolyn to perform the lion's share. She takes these responsibilities seriously and handles them with efficiency. Yet her heart aches—sometimes screams out to her—with a desire to build a more intimate relationship with her mom.

Mom's life was not easy. With five children to raise and Dad away on business a lot, Carolyn's mom was clearly the center of the family. She organized everything and everyone. Carolyn remembers that the household ran with order and structure: scheduled chores, prompt mealtimes, church on Sunday morning. The rituals of living were engraved in Carolyn's heart and mind at a very young age.

Carolyn was Mom's helper. Carolyn was ever-present, side-by-side with her mom, assisting here and lending a hand there. Very early Carolyn took on household responsibilities with a competence and flair that earned the praise and admiration of the person from whom she craved it most … her mom. They worked in practiced rhythm. They flowed together as if they were one. And as they worked, they shared themselves. Carolyn could say

anything to her mother. Always accepting, always empathetic, always "there," Carolyn's mother was a paragon of compassion, understanding, strength, integrity, and faith. She was a mentor of grand proportion; Carolyn's mother was her confidante.

This wondrous sharing extended through Carolyn's adolescence and well into her young adulthood. Carolyn shared her life with her mother: her courtship, her wedding, her early married years, the birth of her three children, difficulties, joys … everything. The closeness was good, fulfilling, comforting—until about two years ago. Carolyn noticed that her time with Mom began to lack something. As the months passed, Carolyn realized that her mom seemed strangely distant. She wasn't there for Carolyn as she had been.

Once a person who only seemed concerned for others, Carolyn's mom began to focus on herself. Her conversations became egocentric. She talked about herself—particularly her health or lack of it—and seemed to dismiss Carolyn's life entirely. Carolyn wasn't used to forcing conversation with her mom. She certainly had to inject her own issues into their interchange. The more Carolyn tried to push it from her mind, the more it would resurface again on the next visit. What was going on? What had befallen her mother to make her act so unlike her former

self? Carolyn had lost her best friend and confidante; she had lost part of herself.

Carolyn grew to resent her mother for the apparently uncaring person she had become. Her mom started to become dependent upon her. At first Mom's requests were minor—stop at the market, get some stamps, run some errands. Gradually, her requests shrilled to demands.

Carolyn began to feel the first tugs of her mother's manipulation. Then came the day of the first big "blow-up," when Carolyn's frustration escalated into anger. The months of piled-up feelings gushed out in a barrage of emotion. It ended as quickly as it had started, but even so, Carolyn cried herself to sleep that night, vowing never again to let out her inner feelings. From now on, she would wall-up her internal tensions, close-off her confusion, and simply keep her feelings to herself.

Adult Child Elder Caregivers Need Support

Carolyn's story is not unique. Certainly the personalities are unique, but the themes of personal loss are all too common—dependency, emotional unrest, and intergenerational conflict between two people who share a relationship like no other. A growing myth in our culture is that families are self-

ishly abandoning their aging parents. After some 15 years of dealing with adult child caregivers, my observations are quite the contrary.

Families have cared for aging parents in the past, families care today, and God help us if they don't care tomorrow. The problem I see is not one of abandonment. Rather the major problem is the emotional press of wanting to provide all that one can while having only limited resources. Every caregiver at some time faces limited time, limited finances, limited patience, limited acceptance, limited knowledge, and—most of all—limited support for the caregiving role. Who genuinely understands the plight of the adult child caregiver, much less is ready to render assistance to her?

Numerous studies have researched the strain on caregivers and upon the care receiver. In every case, caregivers have been found to struggle tremendously. In most cases, this struggle is internal, shared with very few others outside of one's spouse and perhaps one's physician. These studies confirm, among other things, that caregivers are more at risk for ill health than are noncaregivers.

In a California-based study, Victor Cicerrelli reported that 27 percent of the adult child caregivers in the sample were emotionally exhausted as a direct consequence of their caregiving role (***Helping***

Elderly Parents: The Role of Adult Children. Auburn House, Greenwood Publishing House, 1981). Fully 30 percent registered being physically worn-out by caregiving. And 75 percent claimed to suffer from significant negative feelings toward their aging parent. I'm inclined to believe that the other 25 percent were simply blocking or denying negative feelings. As you can see, the elder caregiving role is a stressful one indeed.

The Strain-of-Care Inventory

To confirm such findings, I decided to perform my own investigation. I devised an assessment with 15 questions designed to uncover the level and content of the stress that caregivers feel. Before you read this next section, which outlines the results of my national sample of caregivers, take the Strain-of-Care Inventory on the next page. Then compare your responses to the results of the national sample.

✏ **Directions:** Circle the number below each statement or question that seems to convey ***best*** how you feel about dealing with your aging parent right now. Where comments are requested, be as concise and accurate as you can.

1. What is the strongest ***positive*** emotion that you feel toward your aging parent?

_____

2. To what degree do you normally feel this emotion? Circle one.

1 2 3 4 5 6 7 8 9 10

low degree high degree

3. What is the strongest ***negative*** emotion that you feel toward your aging parent?

_____

4. To what degree do you normally feel this emotion? Circle one.

1 2 3 4 5 6 7 8 9 10

low degree high degree

5. What percentage of the time you spend with your aging parent does your positive emotion outweigh your negative emotion? _____%

6. What percentage of the time you spend with your aging parent does your negative emotion outweigh your positive emotion? _____%

7. To what degree have you felt yourself withdraw from your aging parent because of negative emotions that you feel? Circle one.

1 2 3 4 5 6 7 8 9 10
low degree high degree

8. To what degree has tension emerged between you and your siblings, or any of their spouses, because of disagreements over care for your aging parent (in-law)? Circle one.

1 2 3 4 5 6 7 8 9 10
low degree high degree

9. To what degree has dealing with your aging parent (in-law) caused strain in your own marital relationship? Circle one.

1 2 3 4 5 6 7 8 9 10
low degree high degree

10. To what degree does your aging parent (in-law) abuse you? Circle one.

1 2 3 4 5 6 7 8 9 10
low degree high degree

11. Specifically, what forms does this abuse take?

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12. To what degree do you abuse your aging parent (in-law)? Circle one.

1 2 3 4 5 6 7 8 9 10
low degree high degree

13. Specifically, what forms does this abuse take?

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14. To what degree has dealing with your aging parent affected your health either (circle one) ***negatively*** or ***positively?*** Circle degree.

1 2 3 4 5 6 7 8 9 10
low degree high degree

15. What do you do to deal with the "strain of care" you feel as a result of dealing with your aging parent (in-law)?

Here's how the national sample of adult child caregivers responded to the Strain-of-Care Inventory.

Question 1 asked respondents to list the strongest ***positive*** *emotion they feel toward their aging parent. In order of magnitude, these were: love, concern, caring behavior, protectiveness, sympathy, respect, pity (?), empathy, compassion, gratitude, admiration, and responsibility.*

Question 2 asked for an estimate of the intensity of this positive emotion on a scale of 1 (low) to 10 (high). The average intensity of positive emotion given by the respondents was 7.24.

It seems obvious that this sample of caregivers not only loves their aging parents but also wants the best for them. They seem well disposed to honor their parents, willing and ready to shoulder the burden of care that is required. An intensity of 7.24 is significant and indicates that their care is motivated by a strong desire to give their parents the best they can.

Question 3 asked for the strongest ***negative*** *emotion the caregivers feel toward their aging parents as a direct consequence of the caring they give. Again, in order of the frequency, they were: anger, frustration, resentment, annoyance, pity, impatience, aggravation, guilt, sadness, distaste, and helplessness.*

Caregiving as a Spiritual-Growth Forum

She said to herself, "If I only touch His cloak, I will be healed." Matthew 9:21

As I interacted with elder caregivers, I became increasingly aware of a curious phenomenon. Some caregivers were ***growing*** as a result of their elder caregiving. They were not simply coping with the situation; they weren't just protecting themselves from strain of care. Instead of being burdened by their increased responsibilities, they were growing spiritually and personally as a result of it. They were becoming more alert, more energetic, more purposeful—in short, more happy with themselves, with their Lord, and with their lives in general.

This observation intrigued me. How could it be, I questioned, that certain people could become stronger as a result of their elder caregiving? What was different about them? What did they possess that many caregivers didn't seem to have? If there was some special ingredient, some magical talent, or some key to it all that they had somehow discovered, I certainly wanted to know what it was. I was determined to find out their secret!

I began a concerted effort to study these special caregivers. They were easy to pick out in a group. They were the serene ones, the ones who seemed to have it all together. They could offer counsel and guidance without seeming the least bit abrasive. They seemed experienced and knowledgeable, even though they had not been in the business of caregiving for as long as many others in the group. They seemed to radiate peace and strength. They inspired me!

I reasoned that whatever they had, whatever they were using to create this peace and internal calm, was certainly worth pursuing. Perhaps if I discovered their secret, I could even teach it to other caregivers. Wouldn't it be wonderful, I reasoned, to go beyond teaching basic coping skills and enter into a new realm of understanding? Could it be that there were some caregivers who actually used their

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Transforming Disempowering Thinking

Do not judge, or you too will be judged. For in the same way you judge others, you will be judged, and with the measure you use, it will be measured to you. Matthew 7:1–2

Personalities don't change as people grow older," asserted the graduate school professor in gerontology (the study of aging), "they simply become more so!" Thus he summarized the often confusing picture of the bizarre behavior that aging parents can exhibit.

For example, Joyce was puzzled by her mother's lack of motivation, her inability to do almost anything, and her absolute refusal to try even the smallest tasks. Joyce laments, "I can't understand it. The

sitting area in the nursing home is just around the corner from my mother's room. They show movies there each week. All she has to do is to take her walker 25 feet. Yet the more I ask, the more she refuses—she simply refuses to do it! Now, what can I do? I don't understand this at all!"

Expressions of confusion and disbelief are common among the most loving caregivers. When asked if the behavior of the parent is substantially different from behavior in younger years, the usual response is, "No, not different from the ways she used to be, just so much more exaggerated!" This is a truth that we, as adult children, must understand. Mom has not transformed her personality; she has simply modified it. More accurately, she has intensified it to the point where it appears to contradict the way she was. She has constructed a new facade over her existing face—a facade that confuses, confounds, and exasperates the best-intentioned caregivers. It seems that former nicks in the structure are now chasms. Blind spots become barricades. The personality has become magnified, sensationalized, and projected.

> Joyce seems more settled now, realizing that her aging mother is evidently not unique. But just as the slightest relief dawns on her face, she

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Christian Action in Caregiving

Now that I, your Lord and Teacher, have washed your feet, you also should wash one another's feet. John 13:14

Harriet came into my office suffering from a curious sense of agitated anger. She began to unfold the story of how her mother (now 80 years old) had come to visit 15 months ago and never left. The visit was to be a postrecuperative time after her broken hip and rehab in her home city some 450 miles away. However, the visit had somehow turned into a permanent arrangement. Harriet's emotional stability was now twisted to the breaking point.

Harriet's story was complex. She had one sibling, an older brother who lived on the West Coast. Harriet had shouldered the primary caregiving role, making 11 plane trips to see Mother the year she

broke her hip. Harriet got the phone calls in the middle of the night when her mom felt increased pain. Harriet played the mediator between Mother and her doctor, her pharmacist, her minister, her neighbors, the utility companies, and her landlord.

Despite this, Harriet reported oppressive criticism from her mother. Her mom could let nothing go by, making negative comments about virtually every facet of Harriet's life. Harriet's only escape was to vacate her own home at every chance. Yet this criticism was not new; she and her mother had always shared a relationship best described as a "conflicted coalition." They were locked in a mutually damaging emotional hold.

Harriet's response was equally virulent attacks and rebuffs of her mother. Mother and daughter seemed unable to retreat from the battleground. While professing emotional exhaustion, Harriet would confess her equally unshakable drive to "get back" at her mother. She was rationally grasping all of this but was emotionally helpless to let go of her destructive behavior.

Together we analyzed her situation and found some interesting facts that could shed light. Harriet's father died when she was a child. Soon afterwards her brother left for college, leaving her to deal with her mother. Always a dependent, demanding

Disempowering Beliefs

1. I need to be the perfect adult child.
2. My relationship with my mother needs to remain what it always has been.
3. I need to "do it all" for my mother. I must protect her.
4. My mother's needs come before my own.
5. I need to always be in control.

Inaccurate Perceptions

1. I see my life as revolving around my mother … I have no life of my own.
2. I overestimate the gravity of the problems that surround me.
3. I see myself as limitless.
4. I see myself as selfish if I do things for myself.
5. I have an image that my mother will eventually change.

Distorted Thinking

1. I think I shouldn't have any negative feelings toward my mother.
2. I think I must fix the situation.
3. I think I am responsible for my mother; it's my fault when things go wrong.
4. I think I'm not good enough.
5. I think I know what's best for my mother.
6. I think my caregiving work is never finished.