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**CHAPTER 1**

I really want to write this book to you. I have a feeling you might need it right about now. There’s a lot going on, right? The devastating diagnosis of some level of cognitive impairment that has been universally labeled dementia. The realization that you are going to have to step up in a BIG way to make sure your parent is not just tossed away by the medical system, family members, their community, and/or society at large. The coming to grips with all the ways you have to protect your parent from all manner of harm. The social, legal, and medical concerns that you will have to address in a short amount of time. Each of these jobs can be quite daunting. You feel like you’re going to need a team to handle things, but it’s just you. You’re the one in charge of this mission. You’re the one making the decisions and tackling task after task with the goal of providing comfort and security for your parent. I know, you’re exhausted. Just thinking about it all is freaking you out. But take one thing at a time and you’ll get through it all. I hope the things that I share will help you to get through it all with grace and a grateful spirit.

 I am just as overwhelmed by the information that I want to share with you as you are as with the tasks that you have ahead of you. Transitions represent some of the biggest challenges when you’re a caregiver. I don’t like them, but they serve a purpose. They’re necessary for helping us to move from one stage of life to the next. We transition from crawling to walking, from nonverbal to verbal, from adolescence to adulthood. And one of the most challenging transitions, from adult child to parental caregiver.

There was a time when my mother took me to New York to see Broadway performances. She loved the theatre. She loved it so much that she subscribed to a discount ticket program so that we could go to as many shows as possible. The theatre shows told stories that I hadn’t heard about. They were told in an entertaining way. Seeing people acting out the life of a character was an amazing experience. The way that those actors embodied the character was amazing to witness. They are very special people. Their ability to express emotions with such powerful energy that it reaches into the audience and touches parts of them that they didn’t realize existed. We saw dance performances that made me want jete along the subway platform and glissade into the doors of the subway car. I was already a lover of the arts, but those experiences made it so much more intense. I wanted to be on that stage, spreading joy and getting the audience out of their everyday routine for a few moments. The arts have a way of helping people to expand their points of view.

There was a time when my mother took me on trips. She loved to travel. I’m

not talking about a subway ride to coney island although we did that too. I’m

talking about a flight to the Bahamas for carnival. Going to Junkanoo was one of

the trips that I will always remember. Junkanoo is a carnival that showcases Bahamian culture. It features a grand parade with colorful costumes, festive floats,

and lots of dancing and merriment. We stayed at a small bed and breakfast and had fun exploring the island together. I’m not sure from where her love of travel originated. Her home is in the Virgin Islands so maybe that has something to do with it. Taking time to visit relatives back home is something that folks from another country have to consider, especially when children are born abroad. I remember visiting my mother’s childhood home. I distinctly recall the chamber pot. If I had to use the bathroom in the middle of night, I used the pot instead of going outside. Yes, the toilet was outside.

Staying in the small, bare-bones home let me see how far my mother had come. It made me very proud to be the daughter of such a determined person. As I grow older, I realize just how fiercely she had to work to transition from those early years of scarcity to a successful career in another country. Here is a woman who grew up as the eldest of 14 children and a second mother to them all. Although she spent her formative years sharing a small no frills space with several people, she ended up owning her own home and having her own space with indoor plumbing. She worked to be able to show me some of the finer things in life. I never really appreciated her journey until I thought about telling my story about becoming her caregiver.

My story of becoming a caregiver began in 2012. For at least 8 years prior, there

were signs of my mom’s cognitive decline. The clutter in her home was an indication of the confusion in her mind. There were so few open surfaces in the place, it was as if she needed to have all of her possessions in sight at all times. Amongst all those possessions was a foreclosure letter from the bank. We consulted an attorney, but in the end, she only had a couple of months to vacate the property.

Along with the job of clearing the house, I had to figure out where she was going to live. She was desperate to stay in the town in which she was living so my research began with that goal in mind. I found out about a presentation by a local social worker, Nancy. She talked about the kind of issues my mother was facing. The forgetfulness, the fretting, the confusion, the inability to manage a household. She was a resource that I immediately connected with. Turns out she worked at a local adult day center. At the center, her clients spent the day in a safe space, had meals, enjoyed therapeutic activities, and conversation. There were about 15 participating on any given day. I liked that fact that it was a small group. I felt like she wouldn’t get lost in the mix. For the most part, she’s a “don’t rock the boat” kind of gal and may not always express her needs in a large setting. Well, we signed her up for the day center. Thankfully, they provided transportation. I was not living in the same town so I could not have helped with that. She enjoyed to people and the routine.

Nancy told me about a few senior living communities in the area. They ranged in price and amenities. The one that we could afford was not the greatest but kept her in town. I was trying my best to honor her wishes. She shared a room and because of her restlessness her roommate was not a fan. In the beginning stages of her dementia, my mother would not sleep. She would be up worrying all night. If she laid down, it was only for a moment and then she’d be back up again. When she was up, she was fumbling looking through her stuff and verbally proclaiming her woes. “Where’s my bag?” “Where’s my watch?” “Somebody’s taking my things.” “These people are thieving my things.” “Where my check going?” “I’ve got to call the bank and find out what’s going on.” “Where’s my cell phone?” “These people are thieves.” She would complain and call them thieves when talking to me but would smile in their faces every time. In her mind, hiding her things was the answer. When I would come to visit, I would find the things she claimed were stolen in a bag under her bed or in the pocket of one of her coats or stuffed in the back of one of her drawers. Most of the time she was hiding things from herself.

Nancy was not only a great resource regarding eldercare and care of elders with dementia, but she was a nice person. She was available to take my calls and calm my anxieties about this new caregiving territory that I was living in.

I met a lot of nice people as I tried to find out about getting the proper care for my mother. Not only did she need a place to stay, but she needed a particular type of care to keep her going. Regardless of how nice, helpful, or knowledgeable the people were, the beginning of my search for proper care was the beginning of my disappointment in this country’s senior care services.

In general, the experience of assisted living has been challenging to say the least. If I’m not dealing with the lack of affordable quality places, I’m dealing with the lack of proper care. The cost of one of the nicer places is at least $7,000 per month in the Northeast region. That’s the average price for the dementia unit of a franchised assisted living facility. The dementia unit is typically called Memory Care. In memory care, there are a smaller number of residents compared to the general assisted living population. The residents in memory care are unable to complete many of the activities of daily living also known as ADL’s. according to the National Library of Science website <https://www.ncbi.nlm.nih.gov/books/NBK470404/> the basic ADLs include the following categories:

* Ambulating: The extent of an individual’s ability to move from one position to another and walk independently.
* Feeding: The ability of a person to feed oneself.
* Dressing: The ability to select appropriate clothes and to put the clothes on.
* Personal hygiene: The ability to bathe and groom oneself and maintain dental hygiene, nail, and hair care.
* Continence: The ability to control bladder and bowel function
* Toileting: The ability to get to and from the toilet, use it appropriately, and clean oneself.

Learning how each basic ADL affects an individual to care for themselves can help determine whether a patient would need daily assistance. It can also help the elderly or disabled people to determine their eligibility got state and federal assistance programs.

**Instrumental ADLs**

The instrumental ADLs are those that require more complex thinking skills, including organizational skills.

* Transportation and shopping: Ability to procure groceries, attend events, and manage transportation, either via driving or by organizing other means of transport.
* Managing finances: This includes the ability to pay bills and manage financial assets.
* Shopping and meal preparation, ie, everything required to get a meal on the table. It also covers shopping for clothing and other items required for daily life.
* Housecleaning and home maintenance. Cleaning kitchens after eating, maintaining living areas reasonably clean and tidy, and keeping up with home maintenance.
* Managing communication with others: The ability to manage telephone and mail.
* Managing medications: Ability to obtain medications and take them as directed.

The IADL differs from ADL as people often begin asking for outside assistance when these tasks become difficult to manage independently.

You would expect that the quality of care would be equivalent to the amount of money you’re asked to pay these companies. However, that is not always the case. The more services your parent needs, the more vulnerable they are. When there are too few staff members to properly perform the necessary tasks, the residents that need the most are the ones that suffer the most. Seniors who live in the general assisted living unit are more independent, so the lack of staff doesn’t have as much of an impact. Those residents can do most things for themselves. They have a reasonable portion of their mental ability and can handle activities that require complex thinking skills. Most importantly, they have the use of their voice. They can speak up when things are not satisfactory. They are connected to reality, they have an awareness of their surroundings, and their minds are clearer. They are not living in a mind of tangled thoughts and time periods.

I want you to remember the importance of getting away from the role of caregiver. As well as the importance of arranging good care while you’re away.

After our last experience with assisted living, I will never spend money for that service ever again. It’s ashamed that I’m done with Brandywine. I had two very good experiences in the past, but this one was a disaster. The new leadership really dropped the ball when it came to my mother’s care. When I picked her up after a 3 week stay, her feet and legs were swollen because she was retaining fluid, and her blood pressure was sky high. This kind of medical setback is not only upsetting in the moment, but for at least 3 weeks after as she tries to recover from the neglect.

Those places never live up to the brochures and heartfelt promises they present when you meet the marketing person. This is a horrible commentary on how our society treats our elderly. The most vulnerable population in our society are very vulnerable when they do not have the personal resources to arrange for the daily care that they need.

**CHAPTER 2**

I want to share information about dementia and its effects on patients and caregivers by sharing some online resources. First, there is a thorough online resource called Guide to Being a Caregiver at https://www.medicarefaq.com/guide-to-being-a-caregiver. It covers many aspects of what to expect when becoming a caregiver.

Next, the Alzheimer’s website at www.alz.org is a good place to go on a regular basis. There are workshops and events to participate in as well as support groups to help caregivers stay encouraged. They can also subscribe to the Alzheimer’s magazine to stay informed.

Another helpful site is <https://arden-courts.org/virtual-events> where caregivers will find informative live and recorded webinars presented by experienced authorities on the topic of dementia and Alzheimer’s. I did not have a positive in-person experience with this company, but I can highly recommend their virtual learning platform.

From these sites, they will not only learn about the disease, but they’ll learn about all the additional tasks on which they should be focused as they attempt to help their parent.

Another resource is from COPSA / Care2Caregivers <https://care2caregivers.com/help-for-caregivers/educational-guides-and-brochures/> This is part of the Institute for Alzheimer’s Disease and Related Disorders

First, you might notice that something is just not right. Next, you might notice more clutter around the house. Make a note of the incidents that occur. Determine a pattern - this information will be helpful when you seek medical/behavioral advice. BE sure to talk to your parent about the things you’re observing and you’re growing concern. The response will probably, “I’m fine,” but you must be persistent. Nothing is going to be resolved in one or two conversations.

**CHAPTER 3**

You’re going to need strength. The Lord says, “Don’t panic I’m with you. There’s no need to fear for I’m your God. I’ll give you strength. I’ll help you. I’ll hold you steady, keep a firm grip on you.” Isaiah 41:10-12 MSG. You have a lot to contend with. One of the first things is talking to your parent about how their abilities are changing. This conversation is tricky. Your parent is going through a change that they may not recognize yet. If they do recognize that a change is occurring, they may not want to admit it. Breathe. Find your patience. This may take a more than one or two conversations. Imagine if someone told you that you are not able to conduct your life as usual. No, sorry, you can’t be in the house by yourself. Why? Because you might leave the stove on and burn down the house. No, sorry, you can’t drive. Why? Because you got into a lot of accidents this year. You could have hurt yourself or someone else. No, sorry, you can’t walk to the store to buy a few things. Why? Because you ended up getting lost for hours. When I tried to call you, your phone was still in the house.

Like me, I imagine you would have a hard time accepting any kind of restrictions on your life. No matter the reason, you would fight for your independence. So, get ready for that push back and get ready to back off when the conversation is too adversarial. Plan to revisit the conversation when the emotions are less tense. You’re going to have to figure out the best way to transmit your message to your parent. I sat with my mother in an area that had few distractions. Then I spoke t o her in a way that would let her know that I was here to help her live her best life, not destroy her life. I kept the message short and simple. I found that short conversations are the most successful. I always ask her response to what I said. I let her know that her opinion matters. As the disease progressed it was more difficult to obtain an intelligible opinion, but even if I was the one making the final decision, I still asked. Acknowledging that she is still a person, who matters. She’s still a person who has a say in what happens in her life.

 The Lord says, “When he calls to me, I will answer him, I will be with him in trouble, I will rescue him and honor him.” Psalm 91:15 ESV. You are going to have to make a lot of timely decisions in a short time. Each decision has to make sense for your parent’s future comfort and safety, not to mention, your peace of mind. What’s the first step? Get the power to speak on behalf of your parent. Do it now while your parent can understand what’s happening. At some point it’ll more difficult to get any kind of authorization to make decisions on behalf of your parent. This is essential. You are going to need access to financial accounts, medical records, and emails. If your parent is tech savvy and uses online accounts, you need the login information. You may even want to direct important communication to your email address and your mailing address. You do not want to miss any important correspondence that is delivered. Many of them come with a deadline that you do not want to miss. Making the right decision can help to make you life easier and your parent’s life easier for you to manage.

 As you may know, attorneys often specialize in a particular area of law. Your best bet is to find one that specializes in Eldercare law this person can help you to anticipate the kinds of options that are available to your family. If your parent served in the military, you may have opportunities to get discounts on the services that you will be accessing in the upcoming months. If your parent owns property, you’ll have to determine whether to keep or sell. Remember that keeping means costs for property maintenance, taxes, and security. Selling means clearing out the house, dealing with buyers, and lots of paperwork. That’s why it’s so important to have the power to make decisions on your parent’s behalf. Or maybe you’re like me and the property is in foreclosure. That makes things easier. The only thing on the to do list is clearing it all out. Yeah that was a rough month. I’m still paying storage fees for stuff that I don’t remember packing. Yeah, I got to get the unit cleared out and stop wasting money. Be careful of those services that cost you money. If your parent has credit cards and bank accounts get access and consider moving the money to a joint account with both of your names on it. This money is for your parent. Use it to handle costs related to your parent’s needs. If you’re tempted to use it to do other things that don’t relate to your parent, I advise you to give this book and the financial responsibility to someone else. The quality of your parent’s life and their dignity is at stake. Now is the time to do your best. Even if that means handing over the responsibility to someone else. Always remember it’s all about your parent, not you. Your parent is the reason your reading this book. Increasing your knowledge of the disease your parent is facing is one of the many steps that you will face on this journey. You can’t fight what you don’t understand.

 The Lord says, “For I the Lord your God will hold your right hand saying to you fear not, I will help you.” Isaiah 41:13NKJV. Knowing your parent’s diagnosis is a scary moment. Now you have a reason for all the incidents that have been happening to your parent. Now you have an answer to the many questions you’ve asked over and over. “What’s going on?” “Is this a serious condition or just a little forgetfulness?” “How do we deal with this?” Doing your research is going to help both of you to make decisions that focus on the comfort and safety of your parent. There are plenty of resources that will give you a working knowledge of dementia. Reading about caregiving is a good place to start. There is a thorough online resource called Guide to Being a Caregiver that you can find at https://www.medicarefaq.com/guide-to-being-a-caregiver. It covers a lot of the aspects of what to expect when becoming a caregiver. Caregiving is not just the job of ticking off items on a checklist. Yes, there are things that you have to do for your parent on a short- or long-term basis. Yes, you do have to put plans in place to make sure that those things are accomplished in a timely fashion. However, on top of that assignment, you will not only be focused on what to do, but how to do it in a way that preserves your parent’s dignity and mental well-being. Getting along and being in agreeable is going to go a long way on this caregiving journey.

 The www.alz.org site is a good place to go often. On the site you will find many resources, support groups, and webinars that get you informed about the disease and its progression. Another helpful site is <https://arden-courts.org/virtual-events> where you will find informative live and recorded webinars presented by experienced authorities on the topic. I did not have a positive in-person experience with their company, but I can highly recommend their virtual learning offering. From these sites you’ll not only learn about the disease, but you’ll learn about all the additional things on which you should be focused as you help your parent.

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Dr. John Dunlop, a specialist in gerontology was interviewed on a podcast entitled “Think Biblically: Conversation on Faith and Culture.” In the interview, Dr. Dunlop said *“He's using dementia to help develop our characters and transform us. Defeating sin. Many people with dementia, it's a great defeat for their pride. And teaching their caregivers to depend more on him.”* Read or listen to the entire interview at Finding Grace in the Face of Dementia - Think Biblically - Biola University.pdf

“I cry out to God Most High, to God who fulfills his purpose for me.” Psalms 57:2 ESV

  (PSALM 32:7-8 MSB) You are my hiding place; you will protect me from trouble and surround me with songs of deliverance. I will instruct you and teach you in the way you should go; I counsel you and watch over you.

LORD GOD, I need Thee every hour, Most gracious Lord. No Tender voice like Thine, Can peace afford. I need Thee every hour, Stay

thou nearby. Temptations lose their pow'are, When thou are nigh. I need Thee, every hour, In joy or pain. Come quickly

and abide, Or live is vain. I need Thee, every hour, Most Holy One. Oh, make me thine indeed, Thou blessed Son!

  I need Thee, oh I need Thee, Every hour I need Thee! Oh bless me now, my Savior, I come to Thee! In Jesus Name. Amen

The Lord says “When he calls to me, I will answer him, I will be with him in trouble, I will rescue him and honor him.” Psalm 91:15.

**CHAPTER 4**

The purpose of this book is to share my experience as a caregiver. I want it to help them to understand what it means to be a caregiver and whether they want to assume that role for an undetermined amount of time. Once that decision is made, I want to help them how to navigate the challenge of life as a caregiver. Although it’s often thought of as a challenge, changing the way the caregiver thinks about caregiving can uncover opportunities that benefit all parties.

Always remember that this time with your parent won’t last forever. So, you want to make the most of every moment. Think about how to make special moments that you can commit to memory and recall when your days of caregiving are over. Take pictures and place them in places where your parent can see them. I have a digital photo frame onto which I upload images. The images rotate continuously. Talk to your parent about the images when they appear. “Who is that?” “What’s happening in the picture?” Engaging in discussions with your parent is an important part of exercising brain functions that are deteriorating. Another strategy is to label the people in each picture so that your parent can have another way to make a connection. My mother and I took a picture wearing matching Christmas pajamas.

I would recommend starting with a book called “Finding Grace in the Face of Dementia” by Dr. John Dunlop, a specialist in the field of gerontology. In the book, he approaches the topic of dementia from a practical and spiritual perspective. Dr. Dunlop uses his experiences working with many patients and their families in order to make their lives more livable.

**CHAPTER 5**

Build your team as soon as you know something’s not right. I want you to remember that you don’t have to be an expert in everything. Assisted living facilities have their departments and so should you. First, your medical department is important to help you stay well. Use your health care resources to maintain your physical and mental well-being. Regular trips to your general practitioner are essential. Just as you care for your parent’s health, you must care for your own. There may be times when you need to take action to handle a medical issue be it urgent or ongoing. There may be times when you need to handle a more intangible issue be it urgent or ongoing. You may need to talk with a professional to maintain your ability to “keep it together.” Your health is your parent’s lifeline. The healthier you are, the more helpful you can be. Keep in mind, your goal is to help your parent live life with dementia in a way that assures them the maximum level of quality and dignity.

Next, your community outreach department is important to help you maintain your identity. Use this department as your social worker. The resources in this department will help you to continue to be your own person. The demands of being a caregiver can be great. They may be so great that you must consistently put aside the activities and routines that give your life joy and meaning. Finding people and places to assist with caregiving is a challenge. Not only do you have to find the resources that you need, but they must be reliable, competent, and trustworthy. There will be times when you must take a break. Your hope is that they will care for your parent’s physical and mental well-being just as well or better than you do. I hear you asking me, “Where do I find someone like that?” “Well how do I know if that person meets my standard?” However you find a potential caregiver to relieve you periodically, you have to ask some questions before hiring. There’s an article entitled “Senior caregiver interview questions to ask when hiring” that provides a list of interview questions you’ll want to ask a candidate when discussing a position as caregiver for your parent. [*https://www.care.com/c/senior-caregiver-interview-tips*](https://www.care.com/c/senior-caregiver-interview-tips/)

Word of mouth is a good start. Ask the people that you know are in a similar situation. Those people may be family members, church members, colleagues, and/or members of your social or professional organizations. Getting recommendations from people who have experienced what you’re experiencing is a great start to finding the help that you need and have some confidence that things might work out. Remember, you will still have to interview the people that you want to add to your Community Outreach Department. They are your potential employees. You must be as certain as possible that they are a good fit for your family and will provide the help that you need while meeting your standards of care.

Another search option is the doctor. The doctor and their staff have information to share. Just ask. There may be a social worker associated with the office and that person can direct you to some agencies that provide services that may help you to systematize many of your caregiving responsibilities.

You may also try the adult day center and/or senior center in your town as well as the senior services department in your state. These offices can tell you about the caregiving services available to you. Your family may qualify for services a low cost or no cost depending on your eligibility.

Finally, your legal department is important to obtain justice for your family. Even before you have a problem, find a legal representative that will have your back and keep them on board. This may be an attorney who does the work for you or one that advises you about how to do the work for yourself. If you plan to use assisted living facilities, you’re going to need to be ready to be go toe to toe with their administration’s legal department. These facilities make preparations to refute and/or ignore claims of neglect and you should make preparations to move forward with your claims despite their attempts to intimidate you. A letter to the company head is a powerful action. The director of the facility is always interested in maintaining their position and moving up the ladder. A letter from you may endanger those goals. Other powerful actions are social media posts. Along with dragging the facility to people searching for information, you may find other families who experienced the same challenges that you are facing. You can do a lot on your own and with others you may be able to do even more.

**CHAPTER 6**

Imagine this...one day you’re living your life and the next day you’re living with dementia. You don’t have it but you feel like you do because you’re now a caregiver for a parent who’s living with it. No, you didn’t sign up for this, but as an only child, it’s your assignment by default...or is it your assignment by divine. Perspective is everything. You see the change. You know it’s getting worse. Where do you turn when you’re the only one who can step in to protect your loved one’s interests?

Okay you are the only child of a parent living with dementia and life is getting heavier than you ever thought it could be. It’s a lot to wrap your healthy brain around! It’s a lot to wrap your life around. Right now you will be assuming some uncomfortable positions in order to help your loved one. If you’ve ever been in a Yoga class, you know that yoga makes you move your body in unfamiliar ways. Looking at the instructor’s demonstration, you think to yourself, “I can’t get into that position! Never gonna happen!” But then, you just start. Yoga sessions always starts with surveying your body, especially your breath. Your encouraged to breathe deeply. Slow down and be more mindful of your breath. Inhale deeply and feel that oxygen touch every cell in your body. Especially the cells that make up your joints and muscles. With every breath, they learn to lengthen and your ability to stretch increases. More and more of your tension is released and more and more of those poses are possible. After regular sessions, you find the positions are more attainable and you’re set up for more advanced movement.

 Also, yoga doesn’t just focus on stretching the body, it stretches the mind and the spirit. At first you had no way of positioning your body in such a strange manner. You couldn’t believe that you could have ever make it happen. But through trial and error, perseverance, and pure belief that it could happen, it was possible. Okay, so you don’t look exactly like the yoga master….so what. You mastered your limitations. You improved your circumstances. You moved the needle on your expectations. That’s some heavy lifting. Be proud.

 That’s the approach that helped me to deal with the caregiving position that I was called to assume. First I had to breathe. Deeply. Each breath pushed more oxygen throughout my system. I felt renewed. Afterall, breath is life. Breath renews life. Your attitude determines the quality of life you live and how high you soar. There’s a saying that states, “Your attitude determines your altitude.” I had that sign hung up in my classroom when I worked as a teacher. That was often the difference between failure and success for students and staff. It’s the figurative difference between living and dying. I understand the word dying can mean many thing. It can refer to the physical deal of a body. Or the symbolic death of a craving or habit that seems to have a hold over you. You are releasing the need for that craving or habit. Possibly replacing it with another that more productive.

 What I mean here by dying is shriveling up. Becoming less of the person you were before you had to use your energy to care for your parent. Yes that bit of life has to change. If you have dedicated, reliable support than you have a chance to hold on to the way of life that you are accustomed to living. For most of us, this is the greatest challenge. For me, I can do all things…during the day between the hours of 9a-4p. Then, like a parent with school aged children when the clock chimes 4pm, it’s all about the homestead. Get out of yours “school” clothes, wash up for dinner, watch a little TV, take your meds, get ready for bed. At times my Mom’s response to bedtime is “can I just watch the TV for five more minutes.” By that time of the night - I’m talking about 8 or 9pm - I’m exhausted and ready to rest. Breath renews strength.