**Name :** Jacqueline Thomas

**PROPOSED TOPIC: What is your book about? What story can only you tell? (In 5 words or less)**Living with dementia as a caregiver.

**PROPOSED BOOK GENRE: What is your category?**

Non-fiction

**PROPOSED AUDIENCE: Who are your intended readers? Children; Ages :** n/a

**A specific population of adults :** caregivers who are caring for a parent **A certain interest group :** assisted living, alzheimer’s groups,  
**Students or an academic group :** n/a  
**Other \***n/a

**WHAT IS THE PURPOSE OF YOUR BOOK? Finish this statement: :  
The purpose of this book is to ...** . . .share my experience to help adult children 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.

**HOW IS THIS PROJECT DIFFERENT FROM OTHER BOOKS LIKE IT ON THE MARKET? :**

If you have never researched other books like yours on the market, don’t make something up here; do the research! My book is different because it will...  
Not sure yet. However, I want to present caregiving from the perspective of an only child and pinpoint the parts of the Bible to help navigate the challenges.

**Give 5 THEMES THE READERS MIGHT ENCOUNTER WHILE READING YOUR BOOK:**

1. Be observant

**THIS THEME RELATES (directly or indirectly) TO MY OVERALL PURPOSE?**

Yes

2. Address concerns early

**THIS THEME RELATES (directly or indirectly) TO MY OVERALL PURPOSE?**

Yes  
3. Research dementia.

**THIS THEME RELATES (directly or indirectly) TO MY OVERALL PURPOSE?**

Yes

4. Rethink your role as caregiver.

**THIS THEME RELATES (directly or indirectly) TO MY OVERALL PURPOSE?**

Yes

5. Make it easy for yourself and take it easy on yourself.

**THIS THEME RELATES (directly or indirectly) TO MY OVERALL PURPOSE?**

Yes

**EXPANDED TOPIC: Write a 20-word or less summary of what your book is about below. STICK to 20 words or less. If you cannot summarize your book in the words allowed, your focus is likely not narrow enough. :**

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 its getting worse. Where do you turn when you’re the only one who can step in to protect your loved one’s interests?

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 everyone has 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 small community, and/or society at large. The coming to grips with all of 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 you 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 task that you have ahead of you. 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 under stand the 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.

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. Ill give you strength. I’ll help you. I’ll hold you steady, keep a firm grip on you.” Isaiah 41:10. 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 not able to conduct your life as usual. No, sorry, you can’t be in the house by yourself. Why? Because you may leave the stove on and burn down the house. No, sorry, you can’t drive. Why? Because you got into several 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 transit 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. 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, you’re peace of mind. Whats 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. You’re 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 swing to you fear not, I will help you.” Isaiah 41:13. Knowing your parent’s diagnosis is a scary moment. Now you have a reason for all of 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 serous 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 progession. 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 of the additional things on which you should be focused as you help your parent. For a deeper dive into dementia,

It can be quite overwhelming, but having as much information as possible in one or two places is helpful.

\*making it easy on yourself

\*taking it easy on yourself

\*embrace your caregiver calling

\*making the most of every day - there’s something funny somewhere

Chp 1 - “Something’s Not Right”

* 1. Be observant
     + - * First, you might notice that something is just not right. The conversations you have with your parent are repetitive. Saying the same thing or asking the same question over and over again can be your first clue that there’s a problem that needs to be addressed. My Mother’s phrase is “I like your shoes.” She’s such sweet person and she’s always trying to be friendly to anyone she meets. But there are times when she has no filter and just tells it like it is. “Look at that hair. Looks like it hasn’t been combed today.”
         * Next, you might notice some clutter things beWalking in my mother’s house always made me feel claustrophobic. Her place was usually very cluttered. It was as if she needed to see every item that she possessed in order to remember what she had. There was no surface unoccupied. At any time there would be a line of bottles each containing a different type of supplement that she was convinced she needed to cure any number of ills that some ad convinced her she had. There would be stacks of books, magazines, newspapers that she claimed she was planning to read. There would be piles of mail - open and unopened - all awaiting a response. There would be clothes laying on the bed instead of in the drawers or closet where they belong. And of course there were all of the outdated knickknacks taking up space and collecting dust that never goes away. I was always amazed that she was never bothered by any of it. She just worked as much as she could, come home, clear a spot on the bed and slip into a deep sleep. I do mean deep. If I called her at the wrong time, she would not know what she was saying.
         * That was a big concern especially when Pay attention to any predators/scammers that regularly send mail or make phone calls to pressure your loved one to hand over their money, their personal information, and make financial decisions that they are not capable of making. These kind of decisions are so difficult to reverse and even more difficult to recover any funds or any sense of security.
         * Even when she was awake, I was not sure she knew what she was saying because she would undo every improvement that I attempted to make to appearance of her home. Whenever I visited, I tried to clean up but as soon as I left, she was left on her own and she undid everything. But I continued to try to make sense of the disarray. As I did, I found important paperwork that was cast aside, cash that was tucked away in between the pages of books and cash in envelopes as part of the pile of mail. Of all the mail to respond to, she responds to some grifter thief who is funding their own pocketbook instead whatever charity they’re pretending to care about. She can’t be bothered to pay proper bills, but feels it’s necessary to send money in response to the biggest con job ever created.
     + Make a note of the incidents that occur. Determine a pattern - this information will be helpful when you seek medical/behavioral advice
     + Speak to your loved one. Try to face medical issues head on. Be prepared for the denial.
       - * “I’m fine.” That’s my mother’s canned response to the question “How are you?”. When I spoke to her I did not get through. I did not meet her where she was because I didn’t understand where she was. Honestly, I don’t understand where she is now.

Chp 2 - “Trying to Make it Right”

* + - Address the concern early
      * + As soon as I noticed the disorientation and the change in my mother’s behavior, I did my best to address the problem. Talking to my mother about such a major cognitive deterioration was incredibly difficult. Primarily because her cognitive functioning was compromised and her understanding of my concern was not urgent. The best I could do was to do my research. I knew that my mother was not the first person to have experienced this devastating condition and therefore, I am not the first child to have to deal with its devastating consequences. Every Alzheimer’s support group can attest to that. Those groups are full of experiences, resources, knowledge, and advice. When caregivers get together, the problems in the room typically find solutions.
        + I hate dementia! Remember that when you lose your temper; when you get frustrated; when you resent having to do everything for someone who may not seem to appreciate all that you do to keep things moving along smoothly year after year. Remember that when the urge to throw your hands up and abort the mission that has been delivered to you on a tape player like on the television show Mission Impossible. As the recording says "Your mission, if you choose to accept it…” in this case, you had no choice but to accept it. There is no one else who will step up. There is no one else who can legally take responsibility for this person who cannot take responsibility for themselves. There is no one else who is as invested in the well being of this person who is living with dementia. I don't feel there is even a place that will
        + My fear is that some part of me will hate my mother as well. I’ve worked so hard to establish a tiny bit of order in my life and now it’s all upended by dementia and a brain that was not healthy enough to resist it. I feel like a horrible person when my mind goes down this dark path. Caregiving is really tough to
        + Contrary to popular belief, dementia is not a part of the normal aging process. The human body and brain are tremendously complex mechanisms. Any abnormal brain function is going to be the result of infinite factors, many of which are out of our control. However, factors such as diet/nutrition, exercise, stress level, quality and quantity of sleep, having genuine social community, blood pressure level, vision, hearing, and dental health have top everyone’s To Do list. Encouraging loved ones to take control of these aspects of life is important. However, it can be frustrating when they don’t do so effectively, but we have to try. If dementia does appear, blaming the person living with dementia is a tempting, but unproductive behavior. Did I mention that the body and brain are complex mechanisms? We don’t have a manual that is specific to our body. So, like much of life, it is trial and error.
    - Inform your support system…your going to need them Where do you go for help?
    - Come up with a plan.
      * + My friend and colleague moved in to the upstairs apartment in her home. That helped me to feel like someone else who cared would look in on her and let me know when something is off.
    - Speak to your loved one. Try to face legal issues head on. Be prepared for the denial.