**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 think I’m avoiding writing this book. My house is clean, my fridge is orderly, my clothes are laundered because I’m cleaning instead of writing to you.

I want to talk to you about the fact that you have to take care of a parent who is living with dementia.

\*talking to your parent

\*making timely decisions that make sense

\*doing your research

\*being overwhelmed

\*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

I am just as overwhelmed by the information that I want to share with 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. Have you ever buried a memory so deep that you needed a metaphorical shovel to dig deep to unearth it and deal with it.

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 clutterthings 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.

INDIVIDUAL THOUGHTS

The transition was the worst. My mother was not willing to accept the fact that her ability was declining. She did not want to acknowledge that her body was changing as she aged. How was I going to get her to be honest about about her declining cognitive functioning. Here is a woman who lived on her own for most of my life. She’s handled her bills, her work schedule, her education goals, her parental responsibilities and finding places to live. Three times that I remember, she found lodging in someone else’s home. She did her best with what she had. However, at the time, that was a less than ideal situation for me. I hated being in someone else’s home when I stayed at her place.

Eventually she found. A two apartment house and had someone else living in her home this time. The house was a real accomplishment for her. I was very proud that she did such a big thing. But a deeper look revealed a lot of flaws in the place. The floor plan, the basement stairs, and the basement itself was among some of the drawbacks that she didn’t see. r

As the cognitive functioning declined, it was easy for people to talk her into things that were not necessarily beneficial for her situation. She got talked into some bad subscription programs, mortgages, insurance policies, and real estate deal.

The world in her head seems so unencumbered. Since she usually has a giggly, get over it quick kind of demeanor, I hope its as I imagine…a happy place. When I get bogged down with life’s long list of responsibilities I think about booking a trip to LeaLand (that’s what I call the world in her head. I wouldn’t have to be concerned about meetings, reports, or bills. I wouldn’t have to be concerned with the logistics of travel, property maintenance or car care. Smiles, rainbows made of glitter, music, and puppies would surround me like a warm, cozy blanket. No clocks or timepieces of any kind. Time is not a factor. Maybe 5 minutes or 5 hours have gone by …I wouldn’t care. I’m in a lounge chair, snuggled up next to something warm and furry. What could be better? I’d book a trip there in a minute.

I often think about how life is with my Mother and how life will be without her. Sounds a little ghoulish, I know. But it feels like something that I have to do to face the reality of the future. I have to acknowledge that there is a time when the energy that I am using to provide for my Mother’s well-being will have to be used for something else and I’m going to have to figure out what that something else will be. That is always in the back of my mind. I try to keep it from me appreciating the present moments with my Mother and capturing them somehow for a future time when the emptiness needs to be filled.

However when I’m thinking this way I feel like I’m not embracing the present and I’m also distancing myself from the anticipated sadness that I think will accompany at some point. As a caregiver, I feel like I have to detach much of the time because I have to be clear minded in order to take care of business and effectively direct my Mother to do what I need her to do at that time. I can’t be too mushy or nothing would get done.. But its difficult to that turn off.