You Deserve a Break Today!

I drove by the local McDonald’s and had a flashback that really sent me down a rabbit hole. Crazy the thoughts I have sometimes and where those thoughts lead me.

I remember when McDonald’s was built and opened in our small (once rural) town a few years back and Bob wanted to go there and eat. I was opposed to it. Never really gave my negative feelings much thought. I just had other places I would rather eat my meal. I love eating out and a fast-food stop doesn’t constitute eating out for me. Well, unless it’s In-N-Out Burger.

Bob was well into his decline with Dementia, and I was “in charge”. I did all the driving and made all the decisions. Bob usually was very happy just to go along for the ride and never balked at what we did. I was always a take charge person but with Bob’s decline, I was 110% in charge. At least I was if he wasn’t having a total meltdown but that’s a story for another day.

Frequently as we drove by McDonald’s he would ask to go there. And without any thought, I would just say no and tell him that we would go elsewhere, or we would go home and eat. It was never discussed more than that.

Now today, about 4-5 years later, this haunts me a bit. Why didn’t I do what my husband asked? Why did I discount his request repeatedly?

Were there other things that I didn’t give Bob any say in? Did I force feed my decisions on him? And why did I think about this many years later? Lots of questions and not a lot of clarity. But in true Susan fashion I decided that if I journaled on this matter, I might get some clarity and move on from the remorse I’m feeling.

I’m a champion for people with Alzheimer’s/Dementia. I think I can support their caregivers and give them sound advice on how to walk the minefield that is Alzheimer’s/Dementia. One of the things I’m often found to say is to not argue with your loved one. Not to be critical of your loved one’s behaviors. To remember they are still the special person they once were even if they are slipping away day by day. I emphasize treating them with the respect and admiration you once felt. You need to remember that they are not aggravating you on purpose. They don’t want to be the way they are any more than you want them to have this disease. They are unable to express themselves. They can’t explain or argue why they want to go to McDonald’s, but now I realize that if they ask for it, it is important to them.

They are counting on their loved one to take care of all their needs and looking back, I think I had room for improvement. Maybe even in all the 41 years of our marriage and not just in the Dementia years. I can see now that Bob might have thought of me as a bossy person and not just a take charge person!

So, my takeaway from my McDonald’s flashback moment (that lasted a few days) is that we all need to honor our loved ones—be they friends, siblings, neighbors, spouses. If they are healthy or ill. Whether they are young or old. If someone asks for something or wants to do something, and it just isn’t exactly what you want, be willing to compromise and bend. Say yes. Maybe you won’t enjoy the meal, but I know you’ll enjoy the moment.

Being Honest about Lying!!

I learned so many new things as a caregiver for someone with dementia. Things I never had given much thought to before. Things that I never hoped I would need to learn.
Behaviors and skills that seemed almost to go against who I was.

One was a biggie called “therapeutic fibbing”. When I first heard this term, I was more than confused. Basically, it means telling little white lies or partial truths to your loved one who has Alzheimer’s/Dementia. That was totally against my belief system, and it seemed to go against my principles. But I began to do it. A lot.

When Bob would ask me if he could go to my house for lunch (when we were in our house), I would tell him that I was out of food, and it would be best that we stay at his house (which was our house) and have lunch. It was much easier than trying to convince him that I didn’t live elsewhere. He was satisfied. A lie? In a way.

Once Bob didn’t drive and had actually had his license taken away, he would ask where his car or his car keys were. Instead of rehashing that he didn’t have a car or license anymore, I would tell him that the car was getting a repair taken care of or getting detailed or a friend had borrowed it. I just made up a new story each time he asked. He was satisfied. A lie? In a way.

Bob told the story about all the baseball hats he had. He claimed his parents threw a party for him when he played football for the Chargers (I must have missed that era!). Bob claimed that everyone brought him a hat and that’s where his baseball hat collection came from. I agreed and said it was a grand party indeed. He was satisfied. A lie? In a way.

Sometimes Bob would think that an old boss or work associate

was joining us for a meeting, and we needed to get to the meeting place. Often it was a story about it being the police chief or a higher up who needed his help on a big case. Instead of explaining that none of this was happening, I would agree and load Bob up in the car and head somewhere for lunch. Sometimes he would forget about the meeting he was supposedly having by the time we got to the restaurant. If he was still going on and on about the meeting with the police officer, I would secretly talk to the waitress and ask her to come tell Bob that he had just gotten a phone call and the police officer wasn't able to come and he would be in touch for another meeting. He was satisfied. A lie? In a way.

Another lesson learned was that there is no blame or guilt once someone is diagnosed with Alzheimer's/Dementia. You can't be so hard on yourself for your behaviors and actions. You just have to give yourself grace. I can't compare being a caregiver to someone with dementia to any other types of caregiving, but I am sure there is no easy caregiving job. I just know in our situation that there were many times that I didn't handle Bob's caregiving with tender loving care. I am sure there were times that I did not look at him with love in my eyes. I'm sure there were times that my voice as harsh and my words were mean. I am sure there were times when my prayers were more for me than for him. Do I regret these things? Do I blame myself or have guilt? No, I don't.

Now that's the biggest lie yet. Of course, I do

Me and Bob’s 4 children wearing Bob’s most favorite hats!

5 of the Great-Grands wearing Grandpa Bob’s hats!

Facebook Official

My goodness. Bob has been on my mind 24/7 this month. And it's not a bad thing. I think it's because a year ago right now, things were rough. Bob had declined to where he needed help with almost everything. He couldn't hold his spoon to eat or hold his coffee cup without dropping it. He had a terrible time getting into bed and just couldn't figure that out. He would just plop himself into bed and where he landed is where he would sleep. Even if most of his body was hanging off the bed. Once super fastidious, Bob had forgotten how to shave and taking a shower was a very difficult process that he (and I both) dreaded. He was confused over what Fixodent was for and there were times he tried to brush his teeth with his razor. It was so sad to watch the physical decline that most people don't know is associated with Dementia. Yep, the brain just stops being able to tell the body what to do. The body just stops being able to function without the brain directing it.

Bob was on a downhill slide, and it was excruciating to watch. Thinking back to last October/November brings me chills. But it also is a reminder that Bob was not living a life that he would have wanted. Yes, it was time for him to pass and sometimes these memories of the rough times make me realize that I didn't lose a healthy happy Bob, I lost the Bob that was ready to go. Weird as this may sound, that helps a bit. I know how Bob wanted to live and how he was living last October/November was NOT how he would have ever wanted to live. On that issue, I am 100% clear.

But this year, I still have lots of changes to process. I am still not used to my new life without Bob. I'm not miserable. I'm just still trying to sort through my feelings about everything! I can be positive and upbeat and then downtrodden

and miserable in the same hour. I can cry at the drop of a hat over a tiny thing or be perfectly content and smile during the most emotional experiences. Yes, I’m a mixed-up mess.

I’ve read many books about grief– about 5 stages, 10 stages, etc., but I just don’t think that those books cover everything. They barely scratch the surface. Just when I think I’ve worked through most stages, I come across another hurdle or issue. Maybe I’ll write my own book! Maybe my book would have 50 stages of grief or more!

So today I take another big step in this grief process that isn’t in any of the books I’ve read. Today I change my Facebook status to widow. Yep, it’s finally Facebook official. I know it sounds silly, but my stomach is churning a bit. Dare to move ahead. Here I go.

Bob with me and with his daughters Shelly & Julie
Fall 2021

Helicopter Wife!

I did move Bob back home after 9 days. I think the memory care facility was inattentive, understaffed, and uncommunicative. They probably think I was a worrisome helicopter wife—hovering over my guy!!

I don't know if my expectations for his care were too high, but I felt the assurances given about the level of care Bob would receive were not met and that I could take better care of him at home. I could give lots of examples on their lack of care but trust me, Bob wasn't getting top notch attention by any means.

I packed up his little bedroom into laundry baskets and black plastic bags and home he came. The first few days at home were some of the worst days we've ever had. Change is hard for folks with dementia and the bouncing to the facility and back again must have thrown him into a bit of a chaos. I questioned my decision to bring Bob home repeatedly. Questioning my decisions seems to be a common occurrence.

But now that Bob's been home for nearly 2 weeks, I realize that it was the right decision. It's hard to be responsible for him 24/7 but I think it's easier than worrying 24/7! Now if I could just get him to sleep at night instead of the day.

Even though I still feel that he'll need the care provided by an assisted living/memory care facility, it will need to be "the right place". So, Bob continues to be on the waiting list for that place and I will do my best to take care of him in our home until there's a room available for him. Waiting on God's perfect timing. Patiently.

Psalm 27:14 "Wait for the Lord; be str**ong, and let your heart**

take courage; wait for the Lord!”

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Bob with his son Steve at the care facility~~~~~~~~~~~~~~~~~~Bob with his daughters Shelly & Julie at our home

Welcome September!

I made a lot of decisions in August.

I started with a private caregiver coming to our home a couple of mornings a week so that I could go to a Jazzercise class. BOTH are working out GREAT. I'm a klutz on the jazzercise floor but it's great to get a good workout and clear my head. But most importantly, Bob and caregiver Nicole do well together. She just sits with him while he dozes off and on in his recliner. She fixes him his breakfast. Occasionally she can get Bob outside to walk with his walker but not often. He'd rather sleep. It's sweet to see how he's taken a liking to her, and he is always pleased to see her and has no concern about me leaving. What a blessing. Thanks Nicole!

Then I met with the administrator of a local residential memory care facility. Big step. I had a long list of questions for her, and all were answered. I'm a planner and I like to be able to know what lies ahead if Bob needs to live in a care facility. It was such a helpful meeting for an organizer like me. My sister Christie went along with Bob and me so that I had someone else to listen to the answers and ask about things I forgot. And give me support. Thanks Christie!

My biggest takeaway was something that was said at that meeting—***I will question and have guilt over every decision I make from here on out***. There're no more easy decisions ahead. To have doubt that I'm doing the right thing for Bob and me is the new norm. I just must learn to quiet that voice that constantly chirps in my ear questioning my every thought and move.

At the administrator's suggestion, Bob has spent some time there throughout August without me. A little respite care for me and a little time for them to evaluate his behavior and assess his needs. Bob's disease has progressed to the point

where he doesn’t seem to miss me or be concerned about me being gone. As sad as that is, I’m glad that he wasn’t there worrying about where I was or wondering when I would be back. The staff tells says he’s cooperative there and he’s welcome for daycare anytime. What a huge relief to know there’s a haven for Bob when I have appointments or a place to be where I can’t take him. My blood pressure and stress are already better!

Then I put Bob on their waiting list for a room. What?! **Yes, I put Bob on their waiting list for a room**. Am I really ready for that? Is Bob at the stage that he’s ready for that? I always had a benchmark in mind as to when I might consider placing him in a memory care home and he’s not at that benchmark yet. But where Bob is right now is crazy hard. I just am not sure that I’m able to care for Bob at home and I’m vacillating on just what to do. I never realized how hard caregiving for a person with dementia would be. I know that sounds ridiculous, but I seriously thought I would be able to deal with anything and everything that would be part of caring for my hubby. NOT!!! This is quite the wild ride and I’m not sure I can stay on it!

I have always said that I won’t make any big decisions while I’m tired, anxious, stressed, angry—but guess what? I’m tired, anxious, stressed, and angry every day.

There is no available room for Bob at this time and I have no idea when a room might open. That’s probably good as I’m not sure if we’re ready to take this step. I do know that God has a plan for Bob and for me. A room will open at just the perfect time. I’m trusting in God’s perfect timing.

So, let’s see what September brings!!

Proverbs 6:19
In his heart a man plans his course, but the Lord determines his steps.

Summer Picnic 2021 Bob with 1 o!