Still Bob

I saw a YouTube video recently that said that a good way to describe Dementia is to get a big chalkboard and write down all the things that the person with Dementia can do. And then every day, erase one of those things. Boy, that's real. And so sad.

In my mind, I took a quick inventory of some of the things that "Bob with 1 o" can no longer do on his own. Driving, using a cell or land line, handling his medications, operating the washer and dryer, recognizing the sound of the doorbell or smoke alarm, using the TV remote, understanding a menu, carrying on a conversation that makes much sense, and so much more. The list of items erased would be long and a bit daunting. So much of the chalkboard would be blank. Little by little Dementia is erasing Bob.

So, I flipped a switch in my head and thought I should make a list of the things that aren't erased from that chalkboard.

- Bob still knows me. Most of the time. Even the rare times that he forgets my name he seems to know that he cares for me. He smiles and greets me happily when I enter the room and he is eager to give me three kisses in a row. That's his habit and he hasn't forgotten that!
- Bob still has a deep love for his children, grandchildren, and great grands. Most of the time he has them all mixed up by age and name, but he still speaks proudly of them and any mention of them brings a smile to his face.
- Bob loves his home and feels extremely comfortable here. He doesn't remember where he has lived before here but daily, he mentions how much he loves this house. I take that as a WIN!
- Bob has fond memories of his career on the San Diego

Police Department. His stories don't align with reality very often (he was the police chief of whole United States, he was on the department for 502 years, he has the largest retirement income in the whole world, etc.) but the memories are positive and he has a good feeling about that time in his life. He did love his job and went to work eagerly back in those days. I'm glad he has upbeat recollections even if they're all very mixed up!

- Bob still likes to have an "adventure". Although our bike rides and long walks have been replaced with short strolls with lots of sitting, Bob still enjoys the places we go. Even if it's a place we have visited many times like Lake Murray or Mission Beach, it seems new and exciting to him. Often, he asks me how I heard about these places not realizing that we've been there many times before.
- Bob loves sweets and desserts. Some things just don't change. Daughter Julie recently named him Cookie Monster!
- Bob loves his "stuff" and can't leave home without everything he thinks he needs. And then some. Many years ago, he used to say "Spectacles, Testicles, Wallet, and Watch" and he would check to make sure he had everything he needed when we left the house. Nowadays he continues to be so worried about having what he needs so he takes too much—3 pairs of gloves, 4 face masks, numerous handkerchiefs, his wallet, a money clip, house keys, loose coin, and a non-working Fitbit. Always a jacket or two. And of course, a baseball cap. What was once an organizational trait is now a disaster. He has so much stuff jammed in his pockets that he can't find anything or remember what he even has with him!
- Bob still is an avid TV watcher. Just nowadays, he pays no attention to what he's watching. A Spanish informercial, daytime soap operas, and sporting events of sport or teams that he doesn't even know. He calls

most programs “the news” even if they are Judge Judy or Doctor Phil. Sometimes he watches for hour upon hour without any sound. I don’t mind. I like the quiet time.

- Bob still has Jesus in his heart. This is the biggest constant and I pray that his faith only grows stronger and doesn’t get erased off that chalk board. He enjoys telling people that he wakes up every day and gives thanks to God for letting him live another day. When we say grace at a meal, he’s quick to add his own little version of “Come Lord Jesus be our guest”. He has a sweet childlike faith that shines through the dark cloud that hovers over him.

So…

Will more and more things get erased off the chalkboard? Absolutely. Dementia is progressive and it seems to be picking up speed as it rolls along. Steam rolls along. Steam rolls along down a steep hill.

So…

As I type this, I’m focusing on the Bob that is still here. Changed. Altered. Different. But still Bob.

So…

I’m not mourning the losses or thinking about what’s been wiped off the chalkboard. That’s too painful. I think a big part of my journey with Bob’s journey is accepting the fact that things will never go back to what they used to be. I’m working on that.

So…

Thanks for being on this journey with me. You surely have been a huge blessing on this bumpy ride.





Bob’s many things…

Organized and ready to go before he jams them all in his pockets!

Crying Time Again…

I have endured so much. Does that sound dramatic or what?! Every day is a challenge with the repetition of questions, the confusion, the forgetfulness, and the delusions. I feel like I can roll with the flow pretty darn good. It's been a learning experience, but I've learned to not try to reason with Bob or to change his mind. If he doesn't want to eat, he doesn't eat. If he wants cookies and M&M's three meals a day, then that's what he has. If he wonders who I am and why I am sleeping in his bed, I try to make a joke of how lucky he is to have such a beautiful woman sleeping next to him. If the tells me that he was on the Police Department for 502 years, I congratulate him for a long and happy career. If he wants to watch a Spanish infomercial and call it football, I don't change the channel. If he wants to wear the same clothes three days in a row, I wait until he falls asleep and then I set out clean clothes for the next morning. If he wants to have my deceased parents over for dinner, I tell him that they are coming soon but not tonight. If I must remind him to put on his mask 100 times, I just do it.

But today I snapped. What was it that caused me to have a huge meltdown and end up crying out for God to help me? What was it? **Bob wouldn't brush his teeth**. He claims he has never brushed them before, and he doesn't know how to do it. Bob says the toothpaste doesn't smell good and he doesn't want to put it in his mouth. I dug through the cabinets and found three different types of toothpaste thinking one of them would be the one to spark an interest in brushing his teeth. Nope, none of them was want Bob wanted. So, he methodically and slowly shaved, showered, doused himself with aftershave, sprinkled powder everywhere, and put foot cream on his feet.

But no, he didn't brush his teeth. I know tomorrow he might but still today, he refused.

I did all the wrong things. Tried to reason. Tried to explain. Tired to use logic. Tried to appeal to his common sense. Raised my voice. Got in his face. Tried to convince him that I knew what I was talking about. Tried to convince him he was confused and mixed up. Wrong. Wrong. Wrong.

So now, I've climbed back down off of the ledge I was teetering on and I'm calmly thinking about today's issue. You would think I would have learned by now that whatever Bob does and says is out of his control. It's the disease's fault and not Bob's fault. Being upset with him is a waste of my energy and trying to reason, cajole, or persuade is a total waste of effort. Some lessons are hard to completely learn.

God knows what Bob needs and it is NOT brushing his teeth daily or fighting over brushing his teeth. Bob needs a loving kind wife who cares gently for him in difficult moments. Thanks for answering my prayer when I cried out.

Next time, God, I'll remember to consult you first!



Sleep Tight!

Do I really want to know what is going on in Bob with 1 o's head? It's so hard to know what he's talking about a lot of the time. He either mumbles, uses incomplete sentences, or just mixes things up. He's super repetitive, his comprehension is slow, and he's more and more forgetful. I know none of this is his fault and he can't help it. He's worried as he now notices how hard it is for him to remember anything or even carry on a conversation. But I feel like I'm making huge strides in having compassionate conversations with him.

These are some of the techniques I have learned and some examples.

- **Don't argue.** If Bob says he played professional football for the Raiders and the Chargers, I just go along with it. I say that I bet it was fun and I hope they won lots of games!
- **Don't try to reason.** If Bob says that he was in the Marines for 20 years and the Police Department for 50 ½ years, I don't try to tell him the actual years and try to reason that what he is saying is an impossibility. Especially if you fit in all the college ball and pro football he played! I just say how happy I am that he liked his careers.
- **Don't confront**. If Bob tells a story about meeting my dad in WWI and saving his life, I just roll with it. I want to scream when he tells me this story and calls my dad Joe (which is his dad's name) but I just smile and say, "how interesting" or "thanks for saving his life".

What I do instead is to try to distract him with a different

activity. When he tells me that there are wild animals on our street, I respond with “Do you want some ice cream”. That usually get him away from staring out the front window at the wild beasts.

Often, I will have to just leave the room to avoid any confrontation. That’s my technique when he’s telling me how to set up the Mr. Coffee for the 10th time in just a short time period.

I try to remain cheerful and smile at the stories. It must be pure craziness going on his head to pull together some of the tall tales he tells. I might as well grin and bear it. Who else has a husband that knows everyone he meets on the street or passes in the store? Bob thinks everyone is a past football teammate, fellow cop, or high school buddy. Even if they are in their 20’s, he greets them and tells them that he hasn’t seen them since college and it’s so good to see them again. How can I not smile and enjoy this friendly guy? (as long as he doesn’t try to get close and shake hands with them!)

The best technique is to respond to the feeling instead of his words. This is a whole new technique for me, but it works well at times. If Bob tells me that his dad and mom (both long deceased) are coming here for dinner, I don’t challenge that idea but switch the conversation by saying “I bet you really miss your parents”, “I wish I had met your mom”, or “I remember your dad was super friendly”. The goal is to redirect and discuss the emotions and not the words. It doesn’t work 100% of the time but it really can help.

His reality is so different than mine and I can’t control it. I can only control how I react to him. I’m working on being patient, reassuring, and agreeable. I have even been known to accept the blame for something even if I am not wrong. That’s new for me!

I'm finding that Bob is more agitated and frightened these days. He wants to be reassured that I am right with him and that he can go with me. We are attached at the hip!

I often stay up and watch TV or movies after Bob goes to bed. Last night he really wanted me to come to bed when he did, so I went ahead and joined him in bed. He was so pleased. He gave me a lesson on how he folds the blankets, and which pillows he likes just like it was the first time I've shared his bed. I just rolled along with this lesson—even as he showed me the TV remote control and explained what it was for. I start my Prime Video Movie (A Night in Miami is very worthwhile viewing) and we settled in.

What happened next is one of those things that just comes out of nowhere. There is no way to be prepared for the roller coaster of emotions of living with a husband with dementia.

Bob: Do you have plans for breakfast?

Me: No, we can talk about it in the morning.

Bob: Well, I have $104.00 in my wallet that I've had since I worked for the police. Can you call YOUR WIFE and I'll call MY WIFE and we can see if they want to meet us for breakfast?

Me: (silent gulp) quiet response—Yes, that sounds good.

So, who did he think I was? What was going on in his head? Who did he think was sleeping beside him in his bed? Had he been confused all evening and was that why he was explaining blankets and the remote? Is there a time coming soon that he will not know who I am?

Well, I'll never know. I tossed and turned a ton thinking about how "interesting" our lives have become and how going with the flow is going to need to become my permanent style. Bob seemed to have slept like a baby and he woke this morning with no plans for breakfast.

So, the final thing I must learn is to NOT TAKE ANYTHING BOB SAYS OR DOES PERSONALLY. I've been reminded over and over that once someone is diagnosed with Dementia that they are excused 100% of the time.

So, I wonder who will be sleeping with Bob with 1 o tonight.

I surely hope it's me!



Bob with 1 o January 2021

New Year, New Word.

Here it is again. 2021. A New Year. I'm not a resolution maker but I did enjoy having a word for the year last year. Last year's word was GENTLE and it helped me through many rough spots. (If you want to read that blog and see how GENTLE became my word and what it meant, please take a peak at my old blog GENTLE written in 12/2019)

After having such a great word for the past year, I started thinking about what my word would be this year. A million words popped into my head. Love, peace, kindness, fortitude, attitude, persistence, graciousness, and on and on. None of them seemed to be “my word”.

Then it started…

On New Year’s morning, Good Morning America featured the singing group For King & Country. They sang a great song (Joy) and it was so stirring that I looked it up on YouTube later that day and watched it again. And then again. I loved their energy in the performance and that drew me to it. I really wasn’t thinking about the song title. Yet.

Later that day, I received a text message from a longtime family friend. Her message said she was praying for JOY for Bob and me this coming year. The light bulb went off. Is JOY my word?

So today I opened my daily devotional for caregivers and turned to today’s reading. What is the heading? JOY IN THE MORNING. Flash! I’m now convinced that JOY is my word.

I will be joyful in the Lord. I will be joyful in my life. I will be joyful in being a caregiver. I will be joyful in being a wife. I will be joyful in my dealings with family, friends, and neighbors. I will be joyful with strangers. And when I am not able to muster up that joy, I will remember that JOY is my word. I know God has given me this word for a reason and He will remind me of it frequently.

Each and every day, God will give me something that will be a sign or a hint that He is taking care of me and that will be my reminder to be joyful.

Yes, I am choosing JOY!



Go to Sleep!

The sleep apnea saga continue.

Bob was diagnosed back in October with severe sleep apnea (he has shallow breathing and has 52.3 episodes per hour when he wakes up to catch his breath). His equipment was ordered. With the help of the respiratory therapist, it was determined that Bob should start with the least invasive equipment—the nose pillows. These are the easiest to adjust to. I had been warned that people with Alzheimer's/Dementia do not adjust to the CPAP equipment, but I was upbeat and ready for the challenge. The equipment arrived in early November and the introductory period began.

Knowing that Bob would "fight" trying the CPAP, I tried to cajole him into wanting to give it all a try. Over the course of a week, I reminded him of these things over and over:

- This is incredibly special equipment that was ordered for him by his doctor
- I told him of other family members who wear a CPAP and are doing well due to it
- I called it a breathing machine to make it seem less foreign than calling it a CPAP
- I told him his heart would work better
- I told him how much better he is going to feel
- I told him his brain will work better and his memory will improve
- I told him that he'd be awake more in the day and we could go on more adventures
- I told him he could start by wearing it 5 minutes and work up to wearing it all night long

I also let the equipment sit by his bedside for the week before we attempted to wear it so he might get used to seeing it and accept it as something "normal".

Did any of these techniques work? Heck, no.

Bob would refuse to try. Bob would let me put it on him and then quickly wanted it off. He would wear it for 5 minutes and then pull it off. He would swat at my hand and get angry. He would say that the "colonel" spoke to him and told him that he didn't need to wear it ever again. Bob would tell me that if I liked it so much, I could wear it. He would tell me that he sleeps great.

I spoke with the Kaiser respiratory therapist to see if there were any techniques that they could suggest. She said I had covered all bases. She was able to lower the air pressure but even with the lowest air flow setting, Bob said he couldn't wear it. More like, wouldn't try it.

Then along came my knee replacement surgery and I put all thoughts of getting him to wear the CPAP machine on hold. I felt I had enough going on.

Then comes this morning. Bob had slept from 8 pm to 6 am and then got up this morning and moved to his recliner. Within minutes he is nodding off & on. I sat and visited with him a bit and in between saying a few words, he would fall right back to sleep. Mid-sentence. It so painfully obvious that 10 hours of being in bed isn't providing him much sleep. I left him to sleep in his recliner and headed off to shower and dress.

Bob came into our bedroom looking a bit upset– he told me he thinks he is dying!!!! He goes on to explain that he couldn't wake up and he couldn't make his eyes stay open. He seemed very shook up. I consoled him that he wasn't dying and that he was just sleepy. I attempted to tell him that he could start using the CPAP machine tonight and that he would get good sleep and not feel like he's dying. Did he like that idea? Nope. He said he just needed a nap and he'd be fine. He has slept most of the day since then.

So it is one month post-knee replacement surgery for me and my focus will turn back to Bob and his sleep apnea.

Pray for a breakthrough for us. Bob's physical health and my mental health depend on it.



KINDNESS REALLY MATTERS

It’s amazing how kind words from total strangers can turn your day around.

Bob and I were walking recently at Ocean Beach. Holding hands and slowly strolling. I was using my cane as my left knee is patiently awaiting replacement surgery.

Ocean Beach is quite eccentric. It’s not pristine and there’s an interesting mix of homeless, folks who live in their cars, hippies, fishermen, and surfers. On this day there was even a goat. And then there was us. I am sure we stood out to most as we slowly strolled along the sidewalk heading to the pier.

I caught the eye of a young man who was smiling and staring at us. He said, “You two are cute, have a nice day”. I returned the greeting. You have a nice day, too. I really had a big grin on my face behind my mask as his kind words echoed in my head.

We strolled on down to the pier and started up the long flight of steps. We must take the steps slowly and we both need to hold the railing. A young spry woman quickly passed us by but as she did, she said, “I want what you two have some day”. And on her way, she went. What she saw in us is the us that I forget about sometime. The us that still loves to be together. The us that still holds hands. The us that still looks out for each other. The us that can walk together in silence and be totally happy.

To have two people remind me of what we have was such a huge blessing. They may have seen that we were old and slow and infirmed, but they also saw that we loved each other.

God bless them for reminding us.

“No act of kindness, no matter how small, is ever wasted”

—Aesop


California
3UFE100


OCEAN BEACH


U.S.A.
U.S.A.
U.S.A.

Relentless?

Bob with 1 o has become more and more sleepy and fatigued. He can fall asleep anywhere and anytime. In the car is the most common but he also falls asleep at our dinner table, at restaurants, at doctors' appointments and of course, in his recliner at home.

Sometimes Bob sleeps for a few seconds and sometimes the little nod-off becomes a nap. Sometimes he's talking and mid-sentence his eyes go shut and he's out like a light.

Our primary care doctor has counseled me that Bob's dementia is progressing and along with that comes more and more sleep. The disease of Alzheimer's/Dementia is much more than a memory disease. It is a disease of the brain. And since the brain is the control panel for all your body, every function of one's body is affected. Bob has many dementia related issues, and one is just being tired.

So you think I would just accept that and take it for what it is. But no, I feel compelled to pursue other avenues and take myself down another path, dragging Bob along with me. I started to realize that it is highly possible for Bob to have sleep apnea. He doesn't snore but he does sleep and wake all night long. Sometimes he wakes with a gurgle sound and sometimes he coughs. He is not aware of this and I'm really not sure if it goes on all night. All I know is that he can't keep himself awake in the daytime no matter how long he is in bed "sleeping" at night.

In trying to get Bob tested for sleep apnea, I had to push his primary care doctor a bit. He finally made the referral and told me it was because I was "relentless". I took that as a compliment! Yes, I wanted to make sure that there was not anything we were overlooking that could be done to help Bob. He may live a long time, or his days may be numbered—all I

know is that I want Bob to have the best quality of life he can. Even with dementia.

The physician's assistant at the Sleep Clinic was so helpful and caring. She saw that I needed to have Bob be checked so that I could either move on or move ahead depending upon the diagnosis. She also warned me that dementia patients do not take well to wearing the CPAP Masks that are used for sleep apnea patents. She said that even if it were determined that he has sleep apnea, there is no guarantee that much could be done to resolve it. Sleep apnea patents must want the benefits of the better sleep and that makes them willing to wear a possibly uncomfortable mask. Most patients can understand that cause and effect and understand the benefits of wearing the mask. Not someone with severe dementia. To them its just another thing their caregiver is forcing them to do!

The testing for sleep apnea is much easier than I anticipated. I made Bob's appointment and we attended a class on how to wear the monitoring device and do the testing at home. Seemed simple enough. I thought we were on our way to better sleep for Bob!

Explaining the class and the monitoring device to Bob was the silliest conversations ever. Imagine explaining it to young child. Just a lot of disinterest and blank stares. At bedtime, when I went to help him put on the monitor and finger probe, he protested. I went through the explanation a few more times, always referencing his primary care doctor by name and telling Bob that his doctor was hoping to solve his sleeping problem and needed this overnight test. I know he doesn't care if I'm upset with him, but he wouldn't want to make Dr. Nafes upset! So, he crawled into bed wearing the monitor on his left wrist and with the finger probe firmly attached. Whew…. all was good.

2 ½ hours later, I was reviewing the paperwork on the

equipment and I realized that I had never pushed the START button. Oh my, Bob had been asleep for 21/2 hours with out the monitor doing its job. I was able to push the start button without waking him. Whew… disaster averted.

So we both slept. I thought. At 5 am I woke up when I noticed Bob was getting out of bed. I told him it was ok now to take off the monitor and I would help him. I reached for his hand. Didn't find it the monitor. Checked the other hand. Just in case. Didn't find it. Yes, the monitor was not on either wrist. It was sitting on the nightstand. Bob had no idea as to when he put it there, but he did admit that he took it off. He said he was fine and didn't need to wear it.

I felt so defeated. The equipment is only for a one-time use. Any chance of it collecting the required data was slim. I couldn't be mad at Bob. I was warned that he would have difficulty with the testing equipment—even though I thought it was so simple to do. I just packaged up the equipment and drove to Kaiser Zion to drop it in the drop box. Maybe they will be able to get an adequate reading from the short amount of time that he had it on his wrist. Maybe. Bob slept most of the way there and all the way back home.

So it took all of that long story to get to the important part. At least this is the important part for me.

Was I pushing and trying to get this sleep apnea test for Bob's best interests or mine? Am I expecting him to improve or change? Am I not accepting that he has a rapidly progressing disease that brings so many health issues? Am I still clinging to chances that something can be done to improve his mental and physical health? Do I have unreasonable expectations of his behavior? Am I making things difficult for him to try to make things better for me? Am I considering what is best for Bob? What are my motives?

Being entrusted with the care of another is scary. How do I

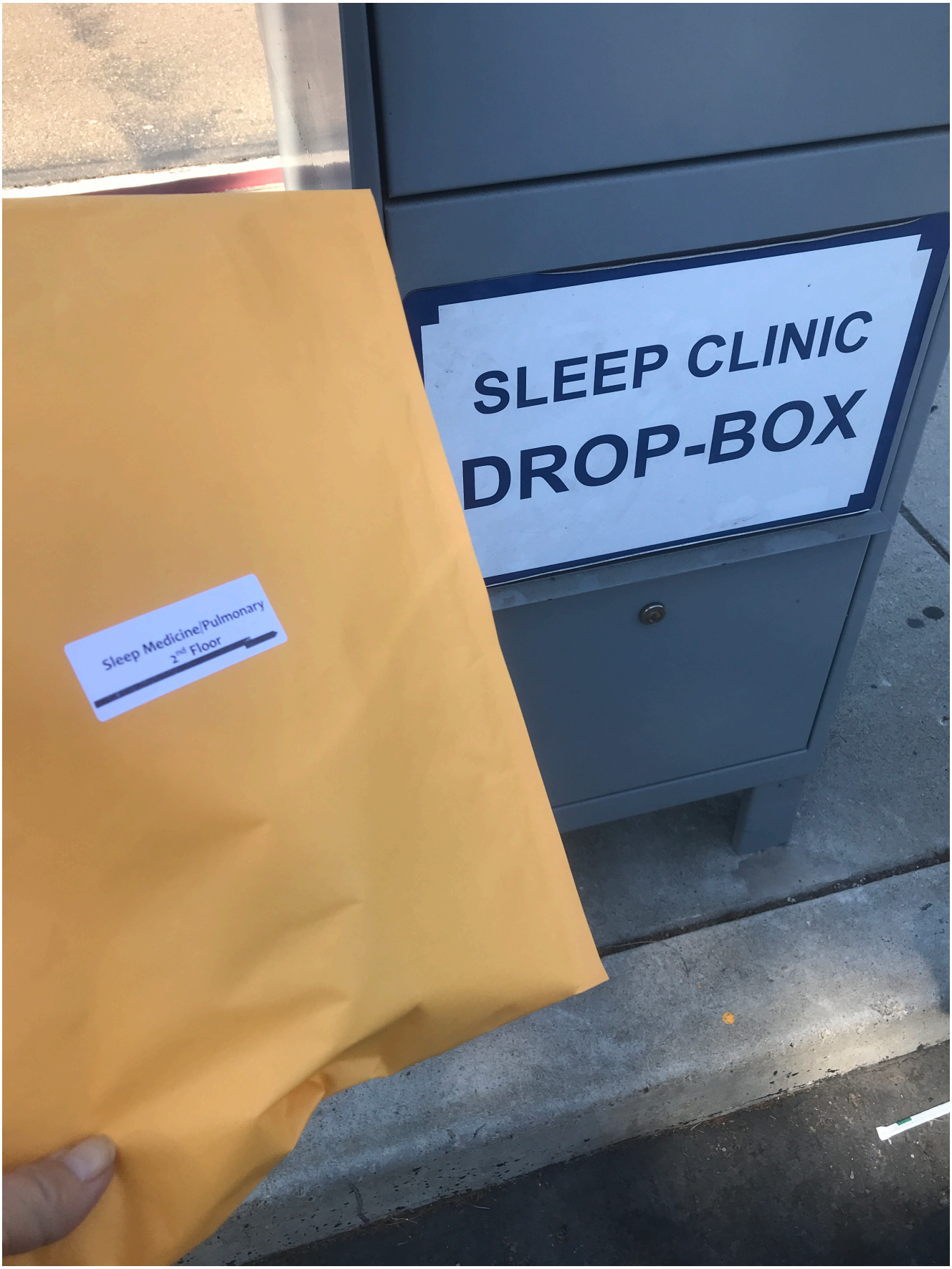
know I’m making the right decisions?

So, as I await the results of the sleep apnea test, this is my prayer:

Dear Heavenly Father, I need wisdom. I have questions and situations to sort out. Please fill my heart with Your wisdom and not my foolish desires. Guide me on the path I should take. Please make me a loving caregiver and not a relentless caregiver.*

*Relentless: Someone who is relentless is determined to do something and refuses to give up, even if what they are doing is unpleasant or cruel.




SLEEP CLINIC
DROP-BOX
Sleep Medicine/Pulmonary
2nd Floor



Susan “Worry” Manis

Our son Kyle always told me that my middle name should be “Worry”. I thought that my being overly concerned, planning ahead relentlessly, obsessing over options, and stressing over details were good things to do. Kyle took them for what they really were—a huge case of being a worry wart!!

As my faith in God has grown, my worries seem to fade a bit. I often place my concerns in God’s hands and sometimes even leave them there. I can rest in my belief that God is in control and try not to worry over those things I can not change. Sometimes it even works, and I am worry free. The Serenity Prayer has become my mantra.

Now on the other hand, Bob never seemed to be too much of a worrier. I guess that might be because it was my “job” and I worried enough for the both of us. Maybe he had worries and concerns that he kept hidden. He was a big tough cop and a man’s man. Maybe he just didn’t openly share his worries like I did.

So now the tables have turned. Flipped upside down would be a better description. Bob worries about everything

- We need to shut our blinds because there are people in our backyard that can see in.
- We need to lock every deadbolt as someone might want to come in our home.
- We need to hide the TV guide and remote away, so no one steals them while we are sleeping.
- We need to move to a different house as the trees behind the house are going to fall and crash our home.
- We need to not park the car under the garage door as its going to come falling down and crash our car.
- We need to drive in a different car lane or even a different road to stay away from boulders on the

hillside.

- We need to watch where we are walking so, we don't get "that sickness" from the red ants.
- We need to not go to close to the ocean because of sharks.
- We need to not use our backyard "fire table" as we will burn our house down.
- We need to turn the picture frames around so that they don't catch on fire from the sun coming in the windows.
- We need to take a coat and gloves with us when we leave the house on a 95 degree day.

The worries are endless.

I attempt to use logic and reason with Bob to no avail. It is like I'm speaking to him in a language he can't understand. That's the truth, actually. He doesn't understand. I try to tell Bob with 1 o that I am going to take care of him, and he need not worry. That doesn't seem to help either. The worries continue.

So as Bob becomes more and more worried, I turn more and more of my concerns over to God. I try to reassure Bob and not make fun of his concerns just as I know that God cares for me in the same way.

I wonder if God is looking down on me and laughing just a little. Is God saying to me, "remember how much you used to worry and I had told you I was in charge, why did you doubt me, why didn't you trust me"?

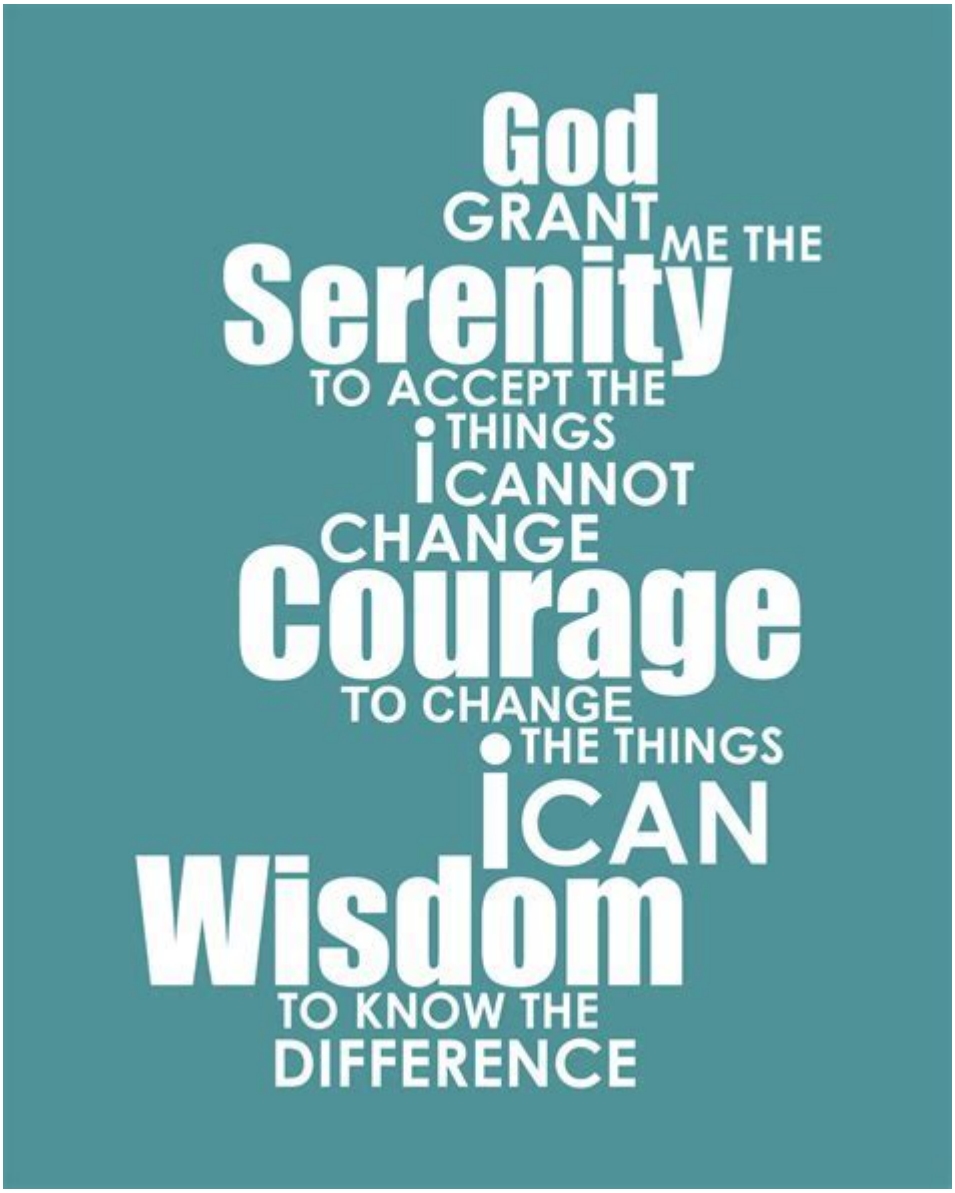
I'm discovering so much as Bob and I go down this path. And those lessons are not always about dementia and caregiving.

Maybe my worry days are not over completely but I'm learning.

Philippians 4:6-7 From The Message

Don't fret or worry. Instead of worrying, pray. Let petitions

and praises shape your worries into prayers, letting God know your concerns. Before you know it, a sense of God's wholeness, everything coming together for good, will come and settle you down. It's wonderful what happens when Christ displaces worry at the center of your life.





Susan & Bob September 2020

Making Moments, Not Memories

Recently I have been thinking a lot about memories. Too much sometimes. I pine over the loss of Bob's memory and cry over the shared memories that are no longer shared. I can really work myself up thinking about all that Bob does not remember and I feel so sad that I can't reminisce about past events with him.

My younger sister Marti and her husband Greg recently spent a week on vacation in nearby La Jolla. They were gracious to spend some time with us and it was wonderful to be with them. The best part was our shared memories and experiences as family. We laughed over things that only our family would find funny. My mom calling the chef "Heavy R" instead of Javier. My dad lifting his little pinky up when he drank tea or coffee. It was so great to have shared experiences and memories. I have been missing that with Bob with 1 o.

Instead of focusing on memories with Bob, I am now focusing on moments. Making enjoyable moments for both Bob and myself is my new goal. Whether or not he remembers these moments (and he usually does not) isn't going to be my concern. I want to live in the moment and make those moments count. I want to show Bob that I love and care for him and make his moments pleasurable. If later in the day, he doesn't remember that we walked at the beach or had a yummy lunch at a café, I'll know that we did, and I'll also know that he enjoyed the moment. Bob with 1 o may not remember the specifics of our day or week but I'm confident that he'll have an overall feeling of enjoyment!

One day this past week Bob woke up at 2 am, confused and thinking he had to be ready for family coming over. He

fretted over being late while I tried to convince him to come back to bed and get some sleep. He got dressed and went to the family room and settled in his comfy chair. Once he fell asleep, I was able to sleep a few more hours. Needless to say, it was a rough start to our day. Once it was really morning, we went to nearby Lindo Lake for a little walk and then on to the Lakeside Café for a nice breakfast on their patio. It could have been a horrible day if I had focused on waking up early and being disrupted by his confusion. Instead, I chose to roll with the flow knowing I could fit a nap in later in the day. My attitude sets the tone for his attitude most times. That was evident today. On our drive home, Bob told me several times that today had been a really nice day! He had forgotten that it had begun with a rough start at 2 am and so did I. What a good moment we both had!

Jeremy Camp sings a beautiful song titled "Keep Me in the Moment" and here's my favorite verse:

Singing Oh Lord keep me in the moment
Help me live with my eyes wide open
'Cause I don't wanna miss what You have for me
Singing Oh Lord show me what matters
Throw away what I'm chasing after
'Cause I don't wanna miss what You have for me
Keep me in the moment
Keep me in the moment
Keep me in the moment
'Cause I don't wanna miss what You have for me

Yes, it will still be hard to not have the shared memories but living one day, one moment, at a time will be my focus.



July 2020 visit from sister Marti and her hubby Greg

HARD LESSON LEARNED

I’m learning more about dementia/Alzheimers than I really ever wanted to know. My personality is such that I want to read, watch documentaries, attend support groups, join in webinars, take Zoom classes, and dig into the subject. Do I think I’ll be better as a caregiver if I do this? I guess. And that’s my goal—to be a loving, gentle, and kind caregiver to Bob with 1 o.

But day to day living with Bob is the biggest way to discover what dementia/Alzheimer’s is really like. No amount of preparing can really prepare you!

I always thought the Bob would be able to hang on to the memories that were important or meaningful. Doesn’t it make sense that special memories have a special place in his heart,

and nothing can erase them? Obviously, I thought those memories would be embedded permanently in one's heart. I know when I think of significant memories, my heart feels the love, pain, pride, happiness, joy, and even the sorrow of those memories. Aren't those memories part of one's inner core?

Well I can tell you that they aren't. They only exist in one's brain and because Bob's brain is so atrophied and damaged, those memories don't exist for him. No amount of reminiscing, picture sharing, or even praying can bring those memories back alive in Bob's brain. They don't exist to him. They are gone just like they never happened.

It's hard to believe that most of memories of the life we have lived over the last 41+ years is missing in his brain. He doesn't know where we met, where we married, where we lived over the years, who are friends were, what we did for fun, what vacations we took, what kind of work I did, what adventures we had with our families, and more. Bob doesn't know important milestones and meaningful periods of our life. I get so angry that those memories of OUR LIFE have been erased. It makes me feel so very sad for BOTH of us.

So, what have I learned about the disease? Dementia is a mean ugly disease. It has robbed Bob of so much. I can't imagine what its like for him to not have those fantastic memories to look back on. I'm not even sure what he thinks about his life. My brain (and heart) are overflowing with significant remembrances that include him and that's what fuels me to keep going and keep lovingly caring for him.

What fuels him? What does he reminisce about? What is he grateful for? What blessings does he count?



“Bob with 1 o” June 2020