

2007

LIVING WITH DEMENTIA

DO YOU KNOW WHERE I LIVE?



© Darryl D Eggleston, 813.677.2871, DarrylD@darryd.com

Watching a loved one slip away mentally is always disheartening. Walking and talking with them while it's happening maybe more so.

Charles Shanabrook, my father-in-law, has always been in great physical shape.

As a boy, he ran to the top of a hill overlooking Los Angeles and flew a homemade kite. In high school, he played first base on the school's team.

Even in his early 80's, he square danced up to 3 nights-a-week, went for long walks and swam daily.

The Dad could build anything that required electronics and most things that did not.

He was an avid life-long ham radio¹ operator. In his youth, he was taught to build ham radio sets from components bought or swapped by his friend, Dutch. Dad spent the next 65 years of his life building and using HAM radios.

In his adulthood, he built boats and houses and truck cabs. One over-the-cab truck camper he built for \$900 and sold it for \$110 ten years later.

He still remembers going arrowhead hunting into the "high desert" of California with his wife, Bunny, and daughter, Peggy.

Both Camping and water skiing were every-weekend occurrences in Peggy's family.

Dad moved to Riverview, Florida, from California in 1996. It cost too much to live out there and he was looking for a less-expensive

For a time, he lived in on Lot 226, at King Richard's Court, in Riverview, but, later he moved to Kings Point in Sun City Center.

¹ Amateur radio, commonly called "ham radio," is a hobby enjoyed by many people throughout the world (as of 2004 about 3 million worldwide, 60,000 in UK, 70,000 in Germany, 5,000 in Norway, 57,000 in Canada, and 700,000 in the USA). A holder of an Amateur Radio license has studied and passed required tests in his or her country and been issued a call sign by its government. This call sign is unique to the operator and is often a source of pride.

There he met and married Della Decker.

They lived together for about 7 years before they separated. Dad was just too hard to live with. What he believed, he stated without regard for hurting anyone's feelings — even his wife's.

When Della asked him to leave, Dad moved to King Richard's Court again and settled into a mobile home on Lot 161.

King Richard's Court is about a mile from our home, so we visited him often and he visited us on occasion.

About a year ago, we began to notice that Dad had dementia.

According to the Alzheimer's Association, dementia is "the loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with a person's daily functioning. Dementia is not a disease itself but rather a group of symptoms that may accompany certain diseases or conditions. Symptoms may also include changes in personality, mood, and behavior. Dementia is irreversible when caused by disease or injury but may be reversible when caused by drugs, alcohol, hormone or vitamin imbalances, or depression."

As far as the doctors can tell, Dad's dementia is irreversible.

We knew it was time to take his car away when he arrived at our front door at 7:15 a.m. one morning. Our dogs heard the doorbell and began their usual terror-inducing barking.

Seeing it was Dad through the glass next to it, I opened the door.

Dad's first words were, "Do you know where I live?"

He had no idea what he was doing at our home or how he got there or how to get back home.

I sat with him for a while and then drove him home.

PegEgg followed in our car and brought me home.

We knew that taking the car from Dad would not be a calm, rational discussion so we developed a strategy to lessen the pain.

We told Dad that PegEgg's car's air conditioner was not working and we needed to borrow his car while it was being repaired. He lent it to us without any hesitation.

For the next few days, he would ask where his car was, but, after that, he quit asking.

From then on, whenever he saw his car in his driveway, he would ask one of us, "Is that your new car?"

We had taken his car none too soon.

For a time, we tried to cope with his dementia by increasing our phone calls and visits to him, but, that was short-lived.

In February, Dad had been on one of his early evening walks around the mobile home park but instead had kept going right out the gate. Apparently attracted by the lights of the shopping mall about a quarter-mile from that gate, he wandered into a Publix grocery store.

Unable to remember what he was doing or how he got there, he sat on a bench outside the Publix's pharmacy. The staff noticed him and assumed he was waiting for someone for the first couple of hours, but, when the store began to close at 10 p.m., a store clerk approached him and engaged him in conversation.

Since Dad only knew his name but not where he lived or what he was doing in the store or anything else of value, the store manager called the Sheriff's Department.

Soon a young deputy came and asked him who he was.

He replied, "I'm Charles Shanabrook."

It was the only information Dad could provide.

On a hunch, the deputy did a search to see if Dad had a registered driver's licence. He did.

On that license was his address at King Richard's Court, so the deputy called the park's manager.

The manager said he knew Dad and that if the deputy would bring Dad home, the manager would call Dad's daughter, Peggy.

So, at 11:30 p.m., we got the call.

We rushed over to Dad's mobile home and had a 30-minute conversation with the deputy. We assured him that we would take Dad to our home that night and make arrangements to ensure that the event was not repeated.

Dad stood there very patiently. Occasionally, Dad would ask PegEgg if he was going to take him home soon.

Since we were standing outside Dad's mobile home, the deputy realized that the situation could only be handled by us and bade us a "good night."

We took Dad to our home overnight and began to plan a long-term strategy that we thought would solve the problem. For the next few days, we changed our schedules to ensure that we visited dad more often.

We tried to persuade him that he should not walk at night and he seemed to agree to it. However, within a few days, we got a call from the Emergency Squad of the local fire department about 6 p.m.

It seems Dad had been walking and fell. He broke his nose.

We rushed over to King Richard's Court to find a fire truck, a rescue vehicle, firemen, medics and many neighbors surrounding Dad who was lying on a stretcher.

As you can imagine, there was a large pool of blood on the ground and Dad's face was bloody although the medics had cleaned him up somewhat.

When he saw PegEgg, he asked, "Are you going to take me home now?"

PegEgg rode with him, in the ambulance, to Brandon Regional Hospital's Emergency Room.

I followed in Dad's van. After about four hours, we brought him home.

It was then that we made our current schedule which I call "The Dad Plan."

I drive to Dad's home every morning at 7 a.m. I help him get dressed and put in his teeth. We go for a long walk along the road, but inside the mobile home park. I fix him breakfast and ensure he's taken his pills.

After breakfast, I'll ask him to watch the news and let me know when the weather comes on. He goes to the TV and watches it, forgetting within 5 minutes that he's to tell me when the weather comes on.

I don't leave him until I'm sure he's settled in front of the TV. I ask him to stay by the phone because his oldest daughter, Cristal, is going to call. Then I leave for my day's activities.

PegEgg visits him at 5 p.m. each day except Tuesday and Friday. (A lady named Debbie watches him on those two days.)

Whoever is watching Dad at night ensures he goes on a long walk, eats a good meal, watches some TV and is put to bed. That person doesn't leave until Dad is in bed. That means never leaving before 8 p.m. and, frequently, somewhat after 8:30 p.m.

It disrupts our schedules, but what else can we do? Dad is family.

Along this journey, we've learned some lessons.

LESSON 1: All requests must be in the positive sense.

One can not say, "Don't chew your pills" because he can no longer translate "do not." If you say, "Don't chew," he begins to chew. One must say, "Swallow this."

LESSON 2: Correcting a dementia victim is a waste of time.

If he says he's 83-years-old, correcting him and pointing out that he's 90-years-old has no influence because he can't remember it. Five minutes later, he's just as likely to report that he's 54-years-old or 18-years-old.

LESSON 3: "The doctor says" has a very beneficial effect.

"*The doctor says you must take these pills*" results in quick acceptance of the need to do so. "*The doctor says you have to be in bed at 8 p.m.*" results in him getting into bed without protest.

LESSON 4: Not knowing where he is does not mean he can't enjoy it.

One morning, he announced that he could not go for a walk. He had to go to "the mill" because he was behind in his work.

I asked him, "Dad, how old are you?"

He quickly replied, "I'm 18, but I've got to get to the mill. I've got work that has to be done this morning." (As a young man, he had worked in a wood-processing mill as an electrician.)

I assured him, "Not today, Dad; you've got the day off. Would you like to go for a walk?"

"Well," he replied, "Yes, let's go for a walk. I'd like that."

By the end of the walk, there was no more talk of work that needed to be done.

When he settled into his chair to watch TV, I asked, "By the way, how old are you, Dad?"

He replied, "I think I'm about 54."

LESSON 5: It doesn't matter what he thought before he got dementia.

For as long as I have known him, he didn't like "Mexicans." (That is a quite common occurrence among California residents which is where he resided most of his life.)

Now, his favorite TV channel is a Hispanic station because, "They've got the best music on this channel."

It doesn't seem to matter that he can not understand a single word they are say; he loves the music.

LESSON 6: One must adapt the plan to the current conditions.

Dad has to have an evening walk or he's likely to get out of bed, in the middle of the night, and go for his walk-about. So when the weather is too hot, we take Dad to Wal-Mart for shopping. There, in the air conditioned comfort, we can do some grocery shopping for him while he gets his exercise.

LESSON 7: This Dad is a great guy.

Before his dementia, Dad was a very stubborn, do-it-my-way kind of guy. He exercised few social graces around family members and would say unflattering things like, “You’ve got to lose a lot of weight,” to me.

Frankly, I didn’t much care for him or to be around him. I tolerated him because he was PegEgg’s Dad.

Now, he’s as gentle as a newborn lamb. Ask him to do just about anything and he’ll comply. If he hesitates, say, “The doctor says...” and he complies without hesitation.

LESSON 8: It doesn’t matter how physically fit you are, when your mind is gone, you’re somewhere else.

Dad is in great physical shape. He may well outlive all of his family members; he just won’t remember it.

LESSON 9: Eating is a challenging race.

Every meal, he eats like someone will remove his plate at any moment.

He barely finishing shoveling in the last spoonful before he is trying to shove in the next.

The solution is two-fold. One, give him a teaspoon (instead of a tablespoon) for his oatmeal. Of course, make sure you’re using a teaspoon as well.

Two, as he begins to raise the next spoonful, ask him a question about a pleasant subject — like, “Did you have oatmeal when you were a kid?” (Dad never tires of answering that question.)

LESSON 10: Love does what love must.

As long as we’re able, we’ll take care of The Dad.

He’s family and one takes care of family.

However it affects our schedule, we’ll make adjustments to make time to take care of Dad.

It’s not what we do, it’s what we are.

We are family.