Hitchhiker's Guide to Parkinson's Disease

Introduction:

This little treatise about our life with Parkinson's disease has been a muse of mine for some time. I skip around a lot during my writing little stories. Many things capture my interest about this disease and many things simply capture my interest hence the title.

Cheryl was diagnosed with Parkinson's disease about 2006 according to my poor notes about this part of our life. A lot of other things were going on. I had decided to semi-retire and teach high school science. That idea never really panned out but it was a great effort. Cheryl pushed me along to that decision. I had been working on an M. Ed. at my own pace and in 2005 I walked away from a perfectly good engineering job to student teach. At the end of that experience she asked what I needed to graduate. It was the spring of 2006 and I needed to take the examine and pay the fees to matriculate. I was done.

We have been each other's cheer leaders all through our marriage. We still are today. It pains me to see what this disease has stolen from her. If it was merely a physical inability that progressed as we aged it might be easier to deal with but In her case she has memory loss, delusion, hallucination, confusion on top of the physical issues. The summary symptom is dementia. The human brain is extremely complex and swims in a soup of complex proteins and other chemicals. When the stasis of this balanced system is disturbed it is heart breaking for the folks surrounding the person who is ill.

An article appeared in my news feed on Google a few years ago. This article, published on the Huffington Post's website (***When Caregivers Are Honest, It Makes Folks VERY Uncomfortable*** **–** Articles and Notes) that made me think, others should be uncomfortable. They do not have to deal with the day to day, the heartbreak, the frustration, the disappointment, the sadness and the feeling of being overwhelmed.

Here I have collected little stories and anecdotes about our life with Cheryl's Parkinson's disease. I have lots of notes and snippets of notes in small journals that I have kept over the years. Somewhere around the end of 2018 I started a blog on WordPress.com. One can do that for free. WordPress merely inserts ads into your publication.

At first I wrote about random topics and transcribed many of the poor journal entries that I had made. In relatively short order I found myself writing about different issues with Cheryl and about Cheryl. I found that as I wrote about our life and difficulties dealing with this disease of Parkinson that I was able to discern, ponder and meditate about the situation we found our selves because of the disease. I found that I was able to calm myself and mentally prepare for the things that were going to repeat and keep coming at us as a couple and help me develop strategies for helping with new behaviors and new physical inabilities as they developed.

We were learning on the fly. Cheryl was rapidly losing her short term memory.

It was about in 2018 that the disease started to run our life. It seemed that some friends and acquaintances backed away. Whether they actively did or not, I cannot say. From my perspective it seemed so.

Over time as a care partner one comes to the reality of care giving, occasionally care receiving, asking for help and dealing with issues as they come up. One realizes that the doctors do their best but they do not know everything. They do not know your spouse, mother, father or sibling as well as you do. They do know that for many people with these characteristics that this drug or this therapy works many times. Only you as a care partner can know what is working for your loved one. You are right up against the trees; the rest of the forest is unimportant. Sometimes you have to help the parkie (person experiencing Parkinson's or those symptoms) and sometimes you do not – Parkinson's disease (PD) – much like cancer, COPD or any other chronic disease is experienced by each patient differently.

Acquaintances and extended family members do not know your spouse, mother, father or sibling as well as you do either. In much the same way as medical personnel, who at least have devoted a great deal of time, education and career, friends and family may imply that they have better knowledge of the situation and symptoms. They do not. Internet searches do not make one an expert at anything. If you have friends who knowingly nod and shake their head as you relate stories about everyday life to them do not become offended as they attempt to give you unsolicited advice. Their heart is in the right place; they are merely ignorant. Offer them a copy of this book. If you have family member who knowingly nods and shakes their head as you relate stories about everyday life to them ask them to sit with your parkie once in a while. It will help them gain perspective and greater understanding. If they choose not to sit with the PD patient because they are too busy, afraid to or think that it is not their job, ask them if they would help in some other way.

I have reprinted the Huffington Post article at the end. It is very well written. I would add to the last paragraph of the article "We don't feel blessed, either. Stop saying, "You're blessed to have her." Please skip to the end and read the article. You will get the gist of where I am coming from when I comment – Parkinson's sucks. (This is Michael J. Fox's comment and I think it to be very apt.)

When this article appeared in 2021 as part of Google's news feed (it does look over your shoulder as you surf the net) I thought – Yes! Absolutely! I know exactly what she is talking about. I am not ashamed of it. I do not feel guilty about it. I am not afraid to tell you how little I want to do this job for my wife with Parkinson's disease who needs my help. Understand that both Sam Parkinson and his disease truly suck, so, although it was never my intent to be a Parkinson care partner, this is the life I was given. It may be part of some superior being's plan but I think at this moment in time that the plan sucks.

As long as Cheryl needs me, I will be here for her but I will never appreciate platitudes or being prayed for as I suppose others think I should. I am neither irreligious nor nonspiritual. I merely believe that the phrase "god helps those who help themselves" just means that self reliance is better than blaming the situation on someone else. To me, praying is another form blaming someone else. People that I know tend to pray for something. (e. g. Pray for good weather.) I meditate and introspect about our life and my reaction to situations and Cheryl's issues. I wish to be better at helping her. I wish that I did not react negatively to some of her demented ideas. (She used to be so clear thinking.) In my little stories and blog posts I spend time thinking about and discerning how I could do better. If this is a form of prayer then so be it. I think of it as a self improvement project. I do want to improve. I do not want to learn enough to be excellent at it.

I think that the only way out is through. I am not writing this as a way to inform the reader of therapies or treatments. It is merely my documentation of ourselves and our way through it all. We are not through it yet. It will be much sadder when we are.

And because I cannot resist doing it, some of my life philosophy is here too in addition to lyrics from songs I think are apt. Carpe Diem! (And maybe a poem or two here and there.)

Where are We Going?

Is it possible to turn a life with Parkinson's disease into a novel? A memoir? Or at least an interesting narrative? (It is an annoying existence.) These ideas came to me in 2021. In a typical discussion about a chronic disease or a memoir about the sufferer information is presented with some chronology. It helps with indicating the disease progression.

Not in this collection of stories, essays and information will that happen. This is a hitchhiker's guide. Cheryl's disease began to be noticeable to her about 2005. It is now 2022. Our story starts a long time ago in a land not so far away named after a guy named Bernard who was declared a saint or maybe the neighborhood was named after a breed of dog.

When I reminisce about our first meeting I have little direct memory. I was a blind date. (Do not worry. This is not a story of our life together but I do have to have a beginning.) I was unfamiliar with the neighborhood that Cheryl lived in – St. Bernard. I did not know there were small cities surrounded by Cincinnati. The concept was a little foreign but I did know about Norwood which was in the same category. The guys I knew that had set up the blind date picnic affair lived in Norwood and somehow knew these girls who lived somewhere else not in Cincinnati as I did not. The girls were from Our

Lady of Angels high school in St. Bernard. Cheryl knew these girls but she attended Immaculate Conception Academy in Oldenburg Indiana. The plot thickens.

Cheryl was on her way to becoming a nun. Blind happenstance placed her in the comfort of friends that evening. Stupid naivete placed me in my car to go to the picnic that night.

I met my wife. Karma? Fate? God's plan? It is a good story. I may not be the best person to write it. My narrative skills are less than satisfactory.

More later in "We met on a Blue Moon in August."

When Hitchhiking make a List and Write a Journal

I started with the list on the next couple pages so that I will not forget to mention some issue or problem that popped up and we had to deal with at that moment. I suspect that I have missed some of these. (The little vignettes here and there from long ago in our early life will just pop into my head occasionally when I am writing.) There occurred new things, symptoms on a daily basis. The previous things hung around to make life more experimental. I am of the belief that something that may interest someone or merely provide the knowledge that you are not alone. You are not the first one to experience this. Here is another couple dealing with a similar issue. This worked for them, perhaps, it will work for us.

And occasionally since a Parkinson patient can carry emotions close to the surface, we just hug and let the emotional aspect flow over us. Carpe Diem. Seize the moment. (My motto)

Whether you are the Parkinson sufferer or merely (ha ha) the care partner, learn from others as much as you can. There is no cure for Parkinson. It is a progressive debilitating disorder. There is no known definitive cause for Parkinson although there is a body of evidence suggesting environmental chemicals (man made) may be causal to the disease. For now care partner's can only aid the patient as best they can. For some herbs and potions help. For some a combination of carbidopa and levodopa works. These last (c/l) come packed together. Levodopa is a dopamine precursor. The human body uses it to make dopamine which is lacking in parkies. The carbidopa aids in reducing the nausea that can come with taking levodopa. It is never pretty.

I have delayed long enough. My list of topics:

- Treatment and drugs tried and tossed
- All the stories
- slow progression
- research study duties

- caregiver duties
  - Driving everywhere
- head massage
- hair worries
- caregiver frustrations
- creeping details
- purse preoccupation
- overnight pads
- incontinence worries
- bed pads and sheets
- laundry
- varieties of laundry
  - extra laundry
- sun-downer's syndrome
- showtime
- Hallucinations
- delusional behavior
- the presence of others
- inability to find names in conversation (aphasia)
- mixing of names during a story
  - told to family
  - told to others
  - caregiver desire to correct misconception (don't do it)

Blogging
- thinking about it all
- writing for oneself
- recurring themes

Is God in there somewhere?
- Who or what is God to me
- what kind of plan is this?
- Philosophy
- mindfulness
- thinking

Helpers
- asking for help
- lowered expectations

Routines
- Weekly
  - laundries

        - clothes
        - bedding
        - towels and other
        - night time emergency
    - cleaning
        - house cleaning
        - hygiene
    - financial & legal
        - check book duties
        - taxes
        - medical insurance
        - POA
        - Medical POA (living will)
        - wills
        - getting the kids involved early
        - ira(s) and other stuff
    - exercise
        - classes and routine
        - creeping apathy – loss of interest
    - church
    - garbage
- Daily
    - pills
    - food (breakfast, lunch, dinner)
    - dressing the bed
    - newspaper
- Monthly
    - Our Meetings
        - support group (PD)
        - support group (caregivers)
        - stock Club (Moneytree) - me
        - Clementines - Cheryl
        - HOA
    - Barber & Hair Salon (4-5 weeks)
- Quarterly or Semi-Annually
    - Doctor visits
        - neurologist (quarterly)
        - family doctor (twice yearly)
        - dentist (twice yearly)

- Yearly
    - Doctor visits
        - eye doctor

Family
- help from children
- help from siblings
- unsolicited help
- helplessness
- death(s)

Entertainment
- parkie
- care partner
- family parties
- family dinners
- sibs dinners

Exercise
- good for parkie
- good for care partner
- physical therapy

Other Topics
- a regular day
- planning frustrations
- taking a trip
- merely being away for some time (caregiver time)

Hallucinations, Delusional behavior, The presence of others = Caregiver frustrations

Today I spent an hour or so on the phone talking to my sister, Joyce. She called about 11 o'clock as I was finishing a loaf of bread dough. We talked for a long time as we usually do when she calls me or I call her. We talked about various things and caught up with each other's activities.

Cheryl could overhear our conversation as I had put the phone on "trucker" as I finished up my dough activity but eventually I turned off the speakerphone feature because it does not work well with her outside walking and me inside talking loudly.

Eventually we finished our conversation. Cheryl moved by me into her office to do her card thing. I could tell by her body language she was angry about something. I checked in on her. She was sitting in her office so I asked if she wanted the light on. She replied no. I remarked that she seemed angry. She said she was because her cards were all a mess.

Her delusional mind did not have a memory of her sitting at her desk last evening sorting and moving her cards around.

I did not have an answer suitable for her to be okay with so I kept my mouth shut. – Carpe Diem.

Oct 9 & 10 2022

I worry more and more about Cheryl's odd evening behaviors. Quite often afterwards she "wants to go home". It breaks my heart that she doesn't know who I am in the evening. It breaks my heart that I cannot find a solution to helping her get out of those behaviors.

This particular behavior is known as Capgras Syndrome – named after the psychologist that first described it, Jeane Capgras. A better description is impostor syndrome.

I think I am developing my own anxieties about helping her at home.

Early – I mean early – thoughts

RANDOM THOUGHTS

I wrote this following piece sometime during my high school senior year. Corny. Yes, but teenage love is wrought with emotion (and bad grammar). The last line of the last paragraph is especially poignant to me. I still feel that way.

"Random Thoughts" is the name given to this essay sometime in 1967.

> *She was relatively tall compared to the other girls there. I hadn't noticed her at first. I had ridden up (with) some other girl and all the other guys seemed to flock around her and this other short blond. The evening wore on and the recollection I have of her is when I noticed her sitting next to me. t Just sitting there! Watching Kelly squirt lighter fluid into the fire.*
>
> *She wasn't looking my way and I gave her the "once over". Hmmmmmm! Not bad! Matter of fact she was damn good looking! "Now what, Paul, you*

> *don't t even know her name and she doesn't know you, How can you strike up a conversation?"*
>
> *So I did a crazy thing. I grabbed her knee and squeezed it. Needless to say she jumped about three feet in the air. (I dare say she probably thought that I was trying to molest her.) But it seemed to shock her enough that we have never been at a loss for words and our whole relationship has blossomed into something that neither she nor*
>
> *I had expected it to.*
>
> *She is approximately five foot five inches tall, She has the most beautiful auburn-brown hair that human eyes have ever seen. Her face is that of a rose-pink flower blossom. This, however, is not all because behind all that physical beauty is the most beautiful soul, the most beautiful mind and the prettiest personality that ever came down the line. I guess that's what I like and love most about that girl. Because she fills a hole in myself and holds up under the strain.*
>
> *pjw*

There is more of course. Somewhere in this period I tried poetry for the first time. I do not remember being so spiritual in high school but I imagine that teens are looking for themselves. (Sorry.)

Dearest Cheryl

Dearest Cheryl, I cannot see
what you ever see in me.

What you are doing at ICA
I know that soon someday,

You will decide, between a nun's life
and that of the world and its strife.

I know that in the near future,
things, for me, won't go smoother.

Rougher and rougher until downhill
but its not mine but God's will.

And another snippet from some English class project:

12) What do I look for most in a boy. (sic) – Cheryl's answer: *Sincerity; Good sense of humor; Likes to do things other than just sitting around; Understanding – I'm able to confide in him*

In retrospect we were deeply in love in our last year in high school. Cheryl's original intention was to become a Sister of St. Francis at Oldenburg in Indiana. She may have been in the process of changing her mind about that when I met her at the end of the summer in 1966. Only she knows that for certain but I do know that she had just broken off an engagement with another boy. She told me that many years later.

Smitten

DREAMS -11:20

The Lenten season continued
throughout the following weeks.
My social life was halted,
my voice began to squeak,

With springtime nearly upon us
and summer overdue,
School wasn't really desired
anarchy was the rule,

The faculty talked of manhood,
of what it must concern,
While the student dreamed of Cheryl
and what his job could earn.

We met, the day before last
on the corner of fifth and vine.
She carried a book of Gatsby
and we sipped a glass of wine.

I asked her about next Friday
about a movie, some food and fun,
She looked at the book of Gatsby
and nodded, that it was done.

We talked of the meaning of life
about goals, dreams and such.
But as she spoke I decided that
I loved her very much.

pjw '67

Holy cow was I smitten with her in my youth. I still feel that way and I still putz around with poetry. I needed an editor then and I still do. (Squeak rhymed with weeks? - sad.)

Fast forward to current times;

PD Haiku

Parkinson's disease
the gift that is giving her
shaking stumbling gait

Parkinson's disease
opportunity to give
kind help lovingly

A Long Trip and Planning

In October of 2019 we traveled to Florida from Ohio to visit my brother who was dealing with recovery from a serious illness. Since they were in the same state, we also visited with Cheryl's sister Janice and her cousin. It took a great deal of planning.

It is probably not possible to over-plan. I discovered this on the trip to Florida in late 2019 to visit family.

Traveling to Florida

From a blog story – In October 2019 I went to visit my brother in at his home in Florida.

In phone conversation earlier in the year Bill told me of several health issues that had cropped up. He had surgery to repair some of those. I became alarmed at that. I realized at the time how little contact we had with each other since Mom's death.

I developed the thought of travel to Florida with Cheryl. She was interested in visiting with her sister Janice and her cousin Mary Kay who had recently moved to Florida with her husband Jay to start a new chapter of their life together.

Travel with a parkie requires much preparation. In addition to pills and documentation in case some piece of the plan fails, our plan had to include rest periods. Over many discussions with Cheryl – I put this on me – I decided it best to drive and spend two to three days traveling. This would limit our time in the car to about six hours a day and allow for resting every few hours dependent on Cheryl's well being at any one time.

Tires changed, oil changed, other things inspected and about $700 later the chariot was ready. Hampton Inns were aligned with the projected stops after the hours traveled for the initial southern leg of the loop. Every possible health apparatus that might be required was staged for loading. The time to go had come.

In our younger years, I enjoyed traveling by car. I still do. I set the cruise to about four miles faster than the speed limit posted and steer. In Georgia that means I am traveling about eleven miles an hour slower than the other traffic. It is peaceful to me. The other vehicles swirl around like water over the pebbles in a brook and move on in an unchoreographed dance that is both majestic and forlorn.

We are off. The car trunk packed with all health conveniences required for a parkie. And food for the trip in the backseat. This has always been our method of travel. Cheryl gets out the map for the current State that we are traveling through and puts it on her lap to navigate. As we are driving along discussing things, it becomes apparent that she can no longer read a map. This is unfortunate. I don't need a map most of the time. But Cheryl would put the map in her lap to keep track of our progress in past trips. Sadly on this trip that would not be possible. I had a new task. I had to keep her lap map synchronized with the travel we did each day. "Where are we?", she would ask while gesturing at the map in her lap. It was an anxiety I did not want her to have. She was constantly worried we were lost. This was something I had not planned for. I had hoped it would be a peaceful trip south to visit family in Florida.

The weather was perfect. This was October. We stopped after about an hour or two of rolling along at various rest stops along the way. I would reassure her that we were not lost. I would show her where we were on her map.

In some parkies, and in this case, Cheryl, there seems a disconnect between time and speed and a sense of distance traveled. These are rudimentary math concepts. To read a map and navigate with it a sense of scaling is needed. Little of this made "sense" to Cheryl. Parkinson's disease had stolen this from her. Lately it seems that much of her cognition has been crippled. As we drove along I pointed out route numbers and towns on the green signs and pointed to her map to help her find the answer to "Where are we?"

Part of the trip was to see how Cheryl traveled. Her brain seems to wander between illusion, delusion, small hallucination and confusion without losing lucidity. The mental aspects of Parkinson's, which every parkie does not get, seem to be be ever so slowly taking over.

There were times when I doubted my decision to make the journey by car. We stopped more often than we did when we were younger. It caused me to realize I was still young in my head. But we stopped anyway.

The stopping was necessary. I needed to stretch my legs. Cheryl needed to stretch her mind. The weather during this trip was magnificent. During most of the stopping we were able to find a shady picnic area that allowed her to lay down for a bit and rest. I had enough pillows and pads in the trunk so that we could turn a bench into a cot for a bit. We walked a bit until she announced that it would be good to lay for a bit.

When we stopped for the night after 5-6 hours of driving and 2-3 hours of stopping, I was on high alert. On a trip that we took approximately two years previous she had a bad reaction to some of her meds which coupled with some hallucinations led to a long night of trouble. It seemed to be a live dream that I had become a part of. She was certain that demons not daemons were flying about in the hotel room and after using the bathroom in the middle of the night, she left to find help. I jumped up to let her back into the room and remained awake for most of the rest of the early morning hours until she fell asleep again. Her vision was real to her. We discussed it and if she closed her eyes she did not she the demons. She closed her eyes tightly and stayed this way for a long while until she calmed down and fell asleep.

Even though she no longer was taking the medicine that she reacted badly to, I was worried that this might come back in the middle of the night in an unfamiliar place. As a part of my stay over package I had several small night lights. Spotted around strategically just enough light to spark the memory — Oh, that’s right, we are heading to Florida. And don’t trip while going to the bathroom!

About handicap accommodations; every state has different rules and expectations for these rooms. Many of these are excellent. The newer Hampton Inns have an outstanding designer of these, although, they are few in number at each facility. In older Hamptons and other operators the rooms have been converted from standard rooms and in this author’s opinion, it does not work. There simply is not enough space.

For a trip out west to attend my nephew’s wedding and visit with my sister.

For Anna

Coffee - to make a whole pot -| use the 1/8 cup in the drawer to the right of the stove and put in 6 scoops (3/4 C.) If I grind whole bean coffee, I put the slider on 8. It makes about the right amount.

Burners ... Cheryl gets confused about which one comes on. If she wants to make tea, the tea bags are in the pantry roll around shelves. Heat some water. After pouring boiling water on tea bag in the cup set the timer for 4 minutes. Cheryl might forget she made tea.

Shower and hair - after Cheryl takes a shower and washes her hair you will have to put conditioner on her hair. It comes in a dropper bottle. She will sit on the bench under the center vanity in the back bathroom. Massage it into the top and back part of her head for a minute or so. It smells like Vicks Vapo rub. :-) use about 1/2 a dropper full. (I always wash my hands afterward because it makes the coffee taste funny.)

Bed making - after Cheryl takes her 7AM pills she often lays down again for 30 minutes or so. After she gets up and is eating breakfast, it's a good time to make the bed. She sometimes lays down after her 10AM meds.

The button to stop the **EXTREMELY LOUD AND ANNOYING** alarm clock is on the back in the middle of the up,down,left,right buttons. - this goes off at 7AM. If it should stop sounding the alarm just turn it off for a bit and then back on. Sometimes it forgets its alarm settings.

Pills .. inner list corrected - I made a mistake with my list. Cheryl takes 1/2 pill of quetiapine (Seraquel) at night to help her sleep. The list in the box is marked up. | always put her 7AM pills in the little glass bowl the night before. I put her vitamins (1 gray & 2 big white football shapes) in a separate little bottle on the kitchen table. She takes those with breakfast.

Breakfast is typically Life cereal with dried cherries and milk. OJ to drink... often two cups. Sometimes Dove chocolate after. Sometimes tea also.

Soap and supplies -- in the hall closet or laundry room. Dishwasher soap is under the sink.

Pills at night – Cheryl typically goes to bed about 10PM or so. Sometimes earlier but try to get her to not take her last group of meds before 9:30PM. I always open the bed for her. I often sit and read for an hour or so in my office. If you watch TV turn the sound way down. Cheryl hears TV voices and thinks we have visitors. Make sure her walker is in the bedroom next to the hamper. Sometimes she needs it at night.

Laying down and ice packs and Tums - sometimes Cheryl's meds attack her. She may lay down, take Tums (2) and use an ice pack wrapped in a towel. Make sure the ice pack gets into freezer afterwards. - or she might just walk around.

Confusion at night ~ you may notice Cheryl gets generally confused about things at night. This often presents around late afternoon and evening as the sun light is less. Rainy dreary weather also... just reassure her that all is okay. She may ask where the kids went. She may call you Jan. She may see others in the room. Ask her who she sees, it often brings her back to the room. She might not have any of these behaviors.

Cable TV

System on/off only turns on TV, Sometimes the cable box goes off press [cbl] and then power to get it back. WIFI password is ******

My Computers

Laptop is windows 10 machine - password is ****** It is slow and takes a while to get started.

Desktop is Debian 10 Linux machine- password is ******

Both use Foxfire as a browser.

Mom's computer is windows 7 - no password

Generally how the day goes

... up at 7AM meds and lay down a bit, cereal with dried cherries breakfast. Shower or just freshen up. 10AM meds and lay down. Up again and watch the View for a bit... If it's an exercise day, class is at noon, your mom will want to go at about 11:30AM. You will be early. Just go with it. If she is having a good day, go somewhere for lunch. Or on non-exercise days maybe go for a walk somewhere. She likes 4:30PM mass on Saturday.

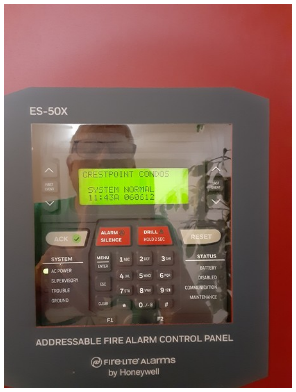
I either cook something or take her somewhere to eat dinner about 5:30-ish. You may not be used to eating at this time during the evening. If your mom eats later that this she often has a hard time at night and does not sleep well.

There are frozen veggies in the freezer and frozen meats of various kinds. Two bowls have potatoes and onions in the pantry. There is rice, quinoa, dried pasta(s) and canned things. I went to the store yesterday and got yogurt, luncheon meat and bread.

Your mom likes English muffins and bagels. There are some of those in the fridge as is salad stuff.

Phone

Jane Pohlman 5136070942 - across hall



Mona Fultz 5134906631 - upstairs

Any emergency 911 :-) The address is **8424 Ridge Pointe Ct**. Go outside and wait for the fire trucks. Take the keys and wave at them – other wise they stop at the middle building which is where their key box is.

Fire alarm

— if the building alarm goes off... sounds like a school alarm. Out in the lobby - The alarm silence button quiets it. The Reading FD will come and look around. The alarm monitor service will call and ask if there really is a fire. :-)

Keys

In the little plastic container... inside and outside door key. Mail box key in dark wood bowl. Cheryl keeps her keys in her purse in the little zipper pocket... mostly. Sometimes she moves them and cannot find them back but they are still in her purse somewhere. Sometimes the mail box key wanders into her purse.

addendum

Newspapers

Two Enquirers and the WSJ show up in front of the outside door in front. Put one Enquirer on the ledge at the top of the steps please. This is Mary Ellen's copy. The others are ours.

Garbage

Garbage goes out on Sunday night. There is no recycle pick up. On Monday morning I go out and put the can back into our garage. I use Jane's key to put her giant bin back in her garage about in the same place as we keep ours. Lock the garage doors to the hallway again. :-)

I could not think if I had forgotten anything so I quit here. And there is always the phone. Anna and I and Cheryl talked in the evenings.

Things that I have Learned

- Do some laundry every day. It makes for a smaller load at the end of the week. Who wants to spend Saturday sorting and folding?
- Sometimes the laundry is a collection of very different pieces of clothing, sheets, towels and whatever. Gentle wash and tumble dry low works for those combo loads.
- Look for Kleenex tissue and other objects before throwing things into the washer.
- The Art of Marriage – true of marriage but care partnering adds another layer of grace.
    - A good marriage must be created.
    - In the art of marriage the little things are the big things;
    - It is never being too old to hold hands.
    - It is remembering to say, "I love you" at least once each day.
    - It is never going to sleep angry.
    - It is having a mutual sense of values and common objectives.
    - It is standing together facing the world.
    - It is forming a circle of love that gathers in the whole family.
    - It is speaking words of appreciation and demonstrating gratitude in thoughtful ways.
    - It is having the capacity to forgive and forget.
    - It is in giving each other an atmosphere in which each can grow.
    - It is finding room for the things of the spirit.
    - It is a common search for the good and the beautiful.
    - It is not only marrying the right partner.
    - It is being the right partner.

- If you are going to make a salad, you will need a bigger bowl that you first thought you would need.
- Look in the trash for clothes before you take it out to the bin.
- As a care partner - Make as much time for yourself as you can while you can.
- Sometimes odd things are in the freezer – combs, the coke from yesterday, Kleenex. When she asks look in there.
- Roasting vegetables in the oven is a good hands-off way to cook them. Most all cook well at 400 – 425 F. Roots and tubers – potatoes, carrots and so on take longer to roast than plants and

seeds – broccoli, green beans, corn. Expect 30 min. for roots, 15 min. for plants and seeds. Save onions for sauteed dishes or saute them separately and add to the roasted veggies at the end.

- Meat cooks fast in a 400 F oven. Keep an eye on it.
- Pound chicken breasts flat before roasting. Soak them in salted water (brine) to thaw.
- You can make all sorts of fun desserts with Krusteaz buttermilk pancake mix. Add about 1 egg for each 1 ½ C. of mix. Use milk instead of water. Add ½ C. unsalted butter and ½ C. of sugar.
- Mustard, honey and a little oil with some vinegar makes a pretty good pasta salad.
- Taste things while you are cooking. This even works with cake batter.
- If you want a cake and got instead a pancake, add some baking power next time. Take notes on disasters.
- People rarely volunteer. Ask them for specific help.
- People rarely say no way when you ask for specific help. They might however tell you a better time for whatever it is. Accept the better time and they will help you again.
- Always ask each week, month, etc. Even if to you it seems like a routine, it is not necessarily to them.
- It is good to have a large flat surface such as a dinning room table or a king size bed nearby when folding sheets from the dryer.
- Position fitted sheets upside down and turn them right side out. Find the corners and push the ones closest to you inside the corners that are away. Tug outward with each pair of corners and flip it over. Lay it flat on the surface and smooth it a little. Fold it up and place it inside the cover sheet that you have already folded.
- Tumble dry low is your friend.
- YouTube is another friend. If you have spilled it someone else has cleaned it up and made a video. Suffer through the gloating ego and try their technique.
- Simplify your chore life as much as you can. For example the few things that you recycle can also be tossed in the trash bin. … one less thing to concern yourself with.
- People with dementia often have really bad memories about trips, events attended and stories. Do not concern yourself with getting the story correct.
- Take time to discern and ponder with mindfulness. Take a deep breath. Maybe two or three.

More Things that I Have Learned

- If you are going to try to get your person with parkinson to speed up to go somewhere make sure you have your act together first.
- What ever schedule that you have in mind is busted, so, move on.
- Some people sleep in occasionally. It is not apathy, just the ordinary need for luxurious life.
- "Church" is merely another name for going somewhere. Just repeat the answer to: Where?
- Do not panic when she asks where we are sleeping or asks if we are going home tomorrow. Tomorrow she will not remember.
- Read her email once a day.
- Casually look in her disorganized office once in awhile to get a feel for where things could be when "I can't find my…" comes up.
- If she wants to make Christmas cookies – let her. Stay close though. She may lose interest or some ingredients partway through.
- Help when asked but do not butt in and tell her what to do. (Even if you know how.)
- Especially with cookie help

This is a continuing list and when I stop to think about it and all the things I have had to learn and do it makes me smile. Frustration creeps in sometimes but I think that most of the time I can push it away. The times that I cannot are about what this disease has taken from her. (August 30, 2022)

Order, Routine and Chaos

I have heard said that a police officer's career is days of pure boredom punctuated with fifteen minutes of shear terror. As a caregiver to one with a chronic disease that tends toward dementia, the experience is similar.

I wrote this when Cheryl was first presenting with odd symptoms of her early dementia and I had no idea how to react or what to do or not do.

In mid-2022, I decided to take a chance change the timing of some of her drugs. The first noticeable effect was she began sleeping through the night. As she slept better her moods, odd behaviors and hallucinations seemed to ease off.

My plan seemed to be working so we moved it to the next level and bought a new bed. Sleep is extremely important to both the care partner and the care receiver.

Strive for routine and accept the chaos.

Put things back in order so that you can find them when asked later.

My Own Reaction Surprises Me

She wants to do it herself. We had a tough for me conversation this morning about issues we trip over as travel the annoying twisty road of Parkinson. It started out as, you know I can still do stuff.

This was a response to me speculating about learning to make my own piecrust instead of buying a commercial piecrust. I will take the path of least resistance every time I can. There are enough things to staff, organize and worry about. If someone has already made the piecrust, I am good with that.

I buy salad in a bag too. Dump and go. Chop a tomato and it is salad. Dressing is in the fridge.

She remarked that she could make a pie and that she knew how to make piecrust. Naturally I forgot about what I have been attempting to practice on a daily basis. I started to enumerate the negatives. I caught myself before I got too far into the ditch along side this partially paved macadam thoroughfare.

It is Lenten season. Instead of chasing some carryout fish fry from our parish we had the makings of tuna casserole. An old time favorite from the Dinner for Two Cookbook by Betty Crocker (You can still find one if you poke around.) Remember Betty Crocker? She is my go to for a lot of things. That seemed like an easy thing and she likes it. I said why don't you make the tuna casserole and we can have the leftover pie for dessert.

She agreed.

We attended a discussion in the afternoon about newer drugs used to treat Parkinson's disease and when they are used and how they worked. When we returned I attended to the laundry and then busied myself with work for my job at our local community college where I teach part time.

She announced she was going to start on the tuna casserole. It was three pm. I spent the next hour listening and worrying and occasionally sneaking a peek into the kitchen twenty feet away. After a few misfires on her part she got started with minor aid from me. She put all the ingredients into a Corning ware bowl and mixed it. She used to know how to start the oven but that knowledge and skill has been lost to Parkinson. I told her which buttons to push and it clicked on.

I went back to work on my project but gave it up for a bit when the oven played its happy tune to announce it was up to temperature and waiting. I went in for the oven placement of the casserole. She put it in but I worried while watching. (Maybe I am a worry wart.)

Bending over to put something in a preheated oven is a scary activity for someone not steady on her feet.

I suppose there is a good mechanical engineering reason for oven doors to open as they do. I have not seen one built so that door opens any other way but down. A standard range winds up with the door about a foot off the floor so that the person reaches down into the oven from three feet away. It looks to me like a disaster waiting to occur. I hovered nearby as she put the casserole into the oven and then put on oven mitts to get something from the fridge.

We ate about an hour ahead of when we usually eat but time and calendar and sunrise and sunset seem to have less meaning for her. It is time for us to start eating dinner at four pm like the rest of the old folks.

I lost it

It is August 26, 2022. Yesterday was a good day. At least it began that way. Cheryl slept a little later. I helped her get up at about 8:30 am.

Just a regular day was beginning. She had exercise class at noon. We came home to a leftover pizza lunch as was the plan.

She had been telling me about getting a new hanging plant at Pipkin's which is a place that neighbor Jane talks about often. She also told me she needed new socks. I proposed we go do a little shopping in the afternoon and she agreed.

A trip to J. C. Penney ensued and we returned home via Pipkin's garden store on Cooper Rd. As we pulled into the parking lot at home my pocket began sounding the alarm for her 4PM meds. She had been telling me that she was tired and wanted to lay down. I suggested she take her meds and rest for a bit.

There are too many distractions for a parkie in our condo-minimum. Cheryl first needs to check for messages on the phone (routine). These days only Hoxworth blood center leaves messages. Sometimes one of the Scam Likely folks will make a mistake and tell me how to save money with Visa, Discover and MasterCard or how to get better Medicare coverage. I am uninterested but Cheryl is worried someone might need her. The meds are ignored while messages are checked. The phone and message retrieval is an overwhelming puzzle to her. She winds up looking at her computer which is off. This leads her to notice the pile of old birthday and note cards on her desk from times past when she was organizing them. She remembers little of this so they are a new discovery. I reminder of her meds from the other room.

As I look back at this little episode I realize that it occurs often when we are home in the afternoon. She acknowledges the alarm on her phone and ignores the meds as she goes back to whatever distraction she has selected (order). I remind her to take her meds and hang out until I see her do it. She comes into the kitchen in response to my entreaty to take her meds. With that done I retrieved two frozen pork chops from the freezer to thaw for dinner. I explained that I intended to make pork chops, some roasted potatoes and broccoli for dinner. Perhaps I would make some tomato chopped salad also. She agreed that would be good and maybe we could eat on the porch.

I reminded her that she had wanted to lay down for a bit and retreated to the porch to read my book for awhile and let the chops thaw. I told Alexa to set a reminder for 5PM and continued with the adventures of Detective Sergeant McAvoy.

Alexa reminded me at five o'clock to get up out of the chair and prepare dinner. Coming in I heard Cheryl's phone alarm reminding her to take her 5PM meds which is a blood pressure medication. When I entered the kitchen I saw that she had emptied the silverware drawer onto the counter and had several glasses of water set up on the other end of the counter. I wrongfully admonished her for getting at the silverware out and asked why she had done that. As she launched into her to meaningless explanation I should have calmed down and accepted it but I did not. I lost it which generated some rage in both of us. (chaos). I put the silverware drawer back together and began to prepare dinner.

She asked what she could do to help and I said that she could set the table outside on the porch. I reminded her that she wanted to sit out on the porch. She responded okay and went off to do something else. Since I was chopping potatoes and breading pork chops I quit paying attention to her while I was doing that. I realized eventually that she was going to set the table in the dining area and when I asked about that she told me that she would set both tables. She insisted that we would need more room for the kids. I must have been smoldering in the background because I flared up again.

The kids are not coming. No kids live with us. I said with louder than normal anxiety in my voice. And besides I only cooked enough for you and me. I put out place mats and plates and silverware and asked her to please sit down. The dinner was ready to come out of the oven and did she want water or a coke with dinner.

I busied myself with getting the food out of the oven and onto serving plates and bowls. When I started putting things onto the table she had wandered off to look on the back porch. She said David was here and I replied that he was not with more volume than was needed. We eventually sat down to the inside table. She served herself ½ a pork chop, some potatoes and broccoli. After she had put some gravy on her plate she started to get up holding the gravy boat. I took it from her and asked where she was going again. She was going to take some gravy to the kids. And I insisted that there were no extra people, kids or otherwise.

She became angry with me and left to get help. I sat for a minute or so and listened for the outside door to slam. It did not so I went looking for her. She had gone upstairs in the front hallway and I think became confused when she did not recognize the upstairs of our old house. I coaxed her down without her falling face first down the steps and suggested we go to the ice cream parlor for dessert. We ate dinner and I cleaned up the dishes.

Aglamesis's for ice cream was a big hit. There were several little people there as always making swift work of their ice cream cones. She had chocolate chip and I had a two-fer dutch chocolate with chocolate sauce and nuts and whipped cream. (I know but it was great.)

We went home and TV for a bit. And later as she became tired she was still agitated and worried about David. She kept looking for David. I suggested that we call David on the phone and we did. I did not give David and preamble but I did explain to him with Cheryl sitting there that she was concerned about his well-being. He talked to her for a bit and assured her that all was well.

After we hung up she said, "David is staying with David and Melissa? Well I guess they have plenty of room."

Today that is all gone past but she did express a slight confusion about David staying with David and Melissa. Somewhere in the back of her mind was a mindfulness of her confusion and to her it was/is scary.

Sometimes it is very hard for the care partner to remain calm. I am still learning this.

Make a Change

Cheryl has some dementia which is a nuisance with her decision making process. Any attempt at speeding her up doesn't seem to work well. She merely gets angry and frustrated with her husband.

And it is hard for her husband to not speed her up. That must be fifty-two years of helping getting in the way of care partnership. (from an August, 2022 blog entry)

This morning I tried to move her along without being pushy. Yes, I can be and have been pushy.

She wakened several times overnight to go to the toilet. I got up to help her once. So, when the seven am medication alarm went off, she ignored it. I got up to remove that annoyance from my ears and get her first dose of stuff for the day. When I returned her snoring indicated disinterest in arising for the day.

I laid back down to see if she would stir again. When I awakened it was eight am. I must have been tired also.

Eventually I left the bedroom to make coffee, get the papers and turn on the news to discover which part of California is on fire. An hour or so later I kissed her awake and she asked me when church started. I told her that she had exercise class at noon. I left to drink more coffee and to listen to the interesting fact that no toilets could be flushed in Mississippi. I returned for another gentle nudge and she got up.

I suggested scrambled eggs and toast for breakfast and she readily agreed. I continued with gentle nudges and quit concerning myself with whether she would be late for her class. She was not late.

The exercise classes she takes at Parkinson Community Fitness are a benefit to her so I make every attempt to get there on time but today I tried a not pushy technique. I call today's strategy "bump and run." I would engage her and nudge her thoughts and then leave. I came back a few minutes later for another bump and run. It worked and neither of us was upset when we left.

And Just When You Think

…. that all is going great something misfires.

Different events in my own life cause me to remember stories from the Bible sometimes. The Bible is full of stories. This story from the new testament, Matthew, I think, talks about two sons reaction to something that their father has asked then to do. The first kid says, Yep. I will be there. And then he does not go. I suppose he goes off to hang with his bros. The story teller does not tell us. The second kid says, not today, Pops, I am hanging with my bros. But after his father leaves he goes and does what his dad asked him to do. The elephant in the room is, which kid did the right thing? The first kid outright lied to his father. What an asshat he is. The second kid did the right thing but was grumpy with his father initially.

It always strikes me that there is not a lot of lead in to this story and the following paragraph does not seem to segue into the story about the tenant farmers killing the owner's son. But I have digressed.

Cheryl slept poorly overnight. When we saw her neurologist he made some adjustments to the meds that are supposed to help with her dementia and memory issues. This was the second night that she had taken the new dosage. She told me at one point her mind was racing. She eventually fell asleep somewhere between 2:30 and 3 am. I did anyway and she did not disturb me awake.

In the morning I let her sleep late by turning off the 7 am alarm. I started to tease her awake at a few minutes before 10 am. She eventually got up at 11 am. While I was waiting for her to get moving, I did a few things that had to happen:

- stuffed envelopes with the ninety or so Christmas cards we send out each year and added a little newsy note like the rest of us that only communicate once in awhile.
- wrapped some of the presents we purchased for the grand children and for some unknown child whose request was hanging on the giving tree at church last week.
- balanced the check book because I forgot to do it on Friday
- paid the property taxes because the escrow account said this was the day
- helped her get out of bed and into the bathroom for meds and the the toilet
- got her breakfast going and helped her out of the kitchen to get freshened up for the day
- helped getting the shower going and made sure she was okay to take a shower by herself
- rubbed the magic stuff in her hair after her shower and hair shampoo
- made the bed

And on and on – making this about me in my head. It is easy to forget and add up this huge column of pluses and equate that with one unsought request. (sad face) Cheryl in the midst of all of this activity as she was combing her hair said the garbage needed to be removed from the small receptacle next to the toilet the receives last night's protection and the occasional Kleenex tissue. It did not I insisted in a volume and timbre that was unnecessary.

So what does all that have to do with the Matthew mystery story. The first kid could have said, yes, I will be right there. I have this other thing to get rid of first. Is that okay, Dad? (Any reasonable father would have accepted this first step to rid oneself of the prior commitment.) The second son could have taken a deep breath and gone to do what his father asked. (He was apparently intending to do it anyway.)

I for my part could chosen either one of these two reactions to Cheryl's need to have the garbage removed. I could have said I will do that in a minute but I need to finish this thing first without the snippy response or I could have merely removed the trash right then. I did remove it a little later. There was no reason for me to feel put upon.

Before that silly reaction by me all was well. Then suddenly something misfired.

Oh well. Carpe Diem.

...from December, 2022

Grace

Recently a classmate and friend of Cheryl passed away. Sister Mary Claire Hausfeld was not in Cheryl's ICA class. Cheryl went to grade school with her and Mary Claire went to OLA high school. She found her vocation after high school. But that is not what I want to tell you about.

In a wonderful and well written obituary about Mary Claire and her life of service S. Delouise Menges writes about Grace in Mary Claire's life and how to recognize grace in our lives. This poem by Marilyn Chandler McEntyre that Mary Claire used in prayer is a beautiful and touching meditation.

How to recognize grace

It takes you by surprise
It comes in odd packages
It sometimes looks like loss
Or mistakes
It acts like rain
Or like a seed
It's both reliable and unpredictable
It's not what you were aiming at
Or what you thought you deserved
It supplies what you need
Not necessarily what you want
It reminds you, you're not in control
And that not being in control is a form of freedom

I have read this over several times and the line that strikes me most is "And that not being in control is a form of freedom".

This life of Parkinson gives that statement new perspective. Little of our life is able to be controlled and I for one would like life to at least be predictable. It is not predictable either and that can be a form of freedom if you let it.

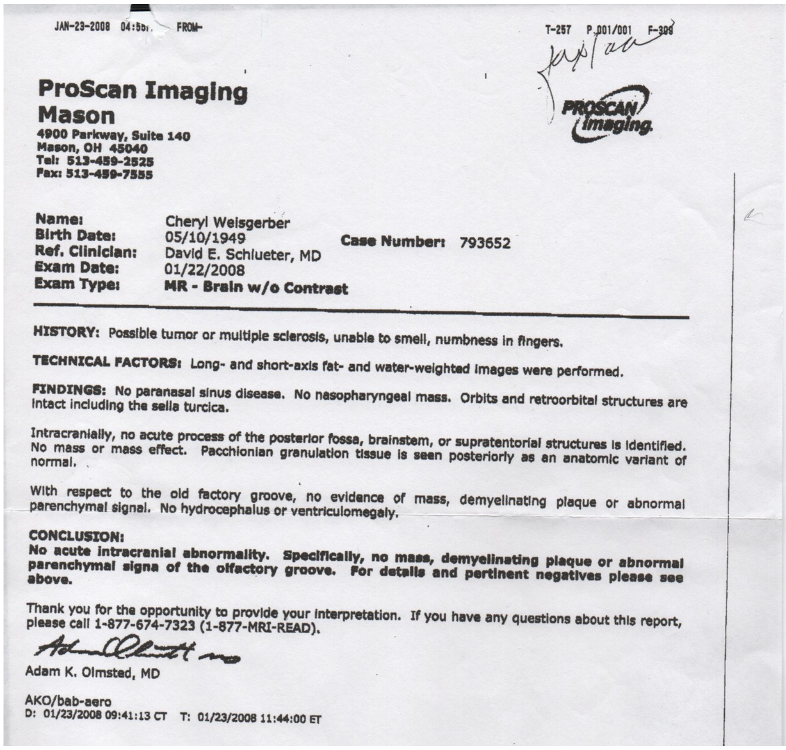
Carpe Diem.

October 2, 2022

Symptoms and Behaviors

Every Parkinson patient has a different set of symptoms. Cheryl is no exception to that. In late 2007 and early 2008 she had taken herself to the family doctor and inquired of him whether it was normal to lose one's sense of smell in later years. She had noticed for some time that she had a diminished sense of smell.

Our doctor sent her for several tests. This is an image of the test results of an MRI performed by an independent imaging company.



JAN-23-2008 04:5 FROM- T-257 P.001/001 F-309

ProScan Imaging
Mason
4900 Parkway, Suite 140
Mason, OH 45040
Tel: 513-459-2525
Fax: 513-459-7555

PROSCAN imaging.

Name: Cheryl Weisgerber
Birth Date: 05/10/1949 **Case Number:** 793652
Ref. Clinician: David E. Schlueter, MD
Exam Date: 01/22/2008
Exam Type: **MR - Brain w/o Contrast**

HISTORY: Possible tumor or multiple sclerosis, unable to smell, numbness in fingers.

TECHNICAL FACTORS: Long- and short-axis fat- and water-weighted images were performed.

FINDINGS: No paranasal sinus disease. No nasopharyngeal mass. Orbits and retroorbital structures are intact including the sella turcica.

Intracranially, no acute process of the posterior fossa, brainstem, or supratentorial structures is identified. No mass or mass effect. Pacchionian granulation tissue is seen posteriorly as an anatomic variant of normal.

With respect to the old factory groove, no evidence of mass, demyelinating plaque or abnormal parenchymal signal. No hydrocephalus or ventriculomegaly.

CONCLUSION:
No acute intracranial abnormality. Specifically, no mass, demyelinating plaque or abnormal parenchymal signa of the olfactory groove. For details and pertinent negatives please see above.

Thank you for the opportunity to provide your interpretation. If you have any questions about this report, please call 1-877-674-7323 (1-877-MRI-READ).

Adam K. Olmsted, MD

AKO/bab-aero
D: 01/23/2008 09:41:13 CT T: 01/23/2008 11:44:00 ET

In 2007 she had a diminished sense of smell which we now know is an early symptom of Parkinson's disease.

From this "nothing there" conclusion from the imaging company, our family doctor suggested she go to visit a neurologist. This guy eventually tried her on 25mg/100mg Carbidopa/Levodopa tablets (Sinemet) after doing a few more tests for other conditions. He told her that if this drug works you have Parkinson's disease. Parkinson is the diagnosis when a bunch of other things able to be tested for are ruled out.

It is a negative diagnosis. A sort of, I don't know but it could be this, diagnosis. Definitely a negative thing that is to be dealt with for the rest of her life. Our doctor told me the same thing about hypercholesterolism that I have. "Take these pills. All will be well." (horseshit)

---/\/\ ---

No sense of smell

The no sense of smell can be a blessing and a curse. If the care partner decides to skip taking a shower and smell like his own sweat for the afternoon, it is a blessing. The wonderful odors of fresh bread baking in the oven going undetected by the parkie nearby make it a curse. Nothing says loving like fresh bread from the oven at dinner time.

Smell is also a memory. As I developed my cooking ability for things other than bread, our home cooked meals started to resemble ones that she had made earlier in our married life.

"These pork chops are really good. I can smell them.", she told me one evening. I too thought I had captured the essence of her earlier cooking and texture. I realized that she probably could not actually smell them but the texture had probably triggered a memory in her. She remembered the smell. I started to focus my meals on those things that we had cooked all though our marriage.

Prior to this I had been spending time on meals that were supposed to be "good" for you. The MIND diet is one of these good for you recipe cook books. Some of the recipes are in my opinion pretty good but none of them are in anyway similar to the meals we fed ourselves while the kids were home and growing up.

An AHA moment had shown itself. I started looking for these as we moved through the morass of PD. I had read a prayer written by a woman in Florida who was dealing with similar issues with her husband. *Edie Kynard's Art* posted the prayer requesting AHA moments in a Facebook group for Parkinson's disease care partners. Edie is a good artist. Her craftiness graces the cover.

Here is her prayer. In () I added my thoughts to make it more male.

> A Wife's Prayer (Husband's) in the life of a Caregiver by Edie Kynard 02/22/20
>
> Lord,as we face this day together, please help me to handle each moment with strength.
>
> May my attitude be positive, my hands gentle when administering help and my heart full of compassion.
>
> (Help me to understand that I do not know all the answers, that only she knows how and what she is feeling. Teach me to be supportive when necessary, to be the explainer when asked, or to be the leader if called

> upon by her to do so, but instill in me the patience, wisdom and empathy to determine which of those is called for this time.)
>
> Please lift me up when I am down, show me the humor in awkward situations and nudge me when I lack understanding. (Do not make your nudges subtle for I am male.)
>
> Send me AHA moments for us to grow through, messages from above for us to share and empathy so that I can step into his (her) shoes and readjust my attitude.
>
> I've asked for a lot Lord, but the most important is my request for forgiveness when, in human error, I tread upon his (her) heart.
>
> So please ...keep my feet planted in solid faith so that I can sow seeds of kindness and not weeds of grumbling toward the many tasks at hand.
>
> Fill me with wisdom so that when we walk this journey together we don't get lost along the way.
>
> In Your holy name, Amen

Edie is still a Facebook friend and we exchange notes from time to time about things. Her husband has passed from this Earth and she carries on without him. I am not particularly religious but I do meditate and ponder the meaning of things. I resist thinking that we are all one big complicated chemical reaction, even if we are.

Aphasia

This one is not part of the parkie iceberg but it seems real to me. Perhaps it is part of the whole creeping dementia thing. Cheryl definitely struggles to find terms, names and words for objects and people in her head. As her partner it is hard to not jump in and supply a word.

Since everything is slower with a PD brain, I try to wait for a synonym or a word I can ask about and get to the real word.

Set a timer for ten seconds and start it running. Do not look at it counting down. Wait for it. Do that in any conversation and once in awhile change the name of something at random. It gives you a sense of what it is like to communicate with someone struggling with aphasia.

Cheryl calls any sort of greeting card a Christmas card. It makes for an amusing conversation sometimes.

As she struggles to find the right name for a person or object it is very hard to not help. Interrupting her thought process is frustrating to her. If I interrupt her and make suggestions the conversation becomes mine and she may lose track of what it was that she was trying to tell me.

As a care partner – patience is a virtue to be cherished. Daily. Perhaps hourly.

Neuropathy

I am Unsure of the Cause

In the middle of the night, very early morning, she gets up and becomes argumentative about staying up. Its about 3AM and I admit to being less than social at 3AM. Today for the first time she told me what was happening to her. She has severe leg cramps and partial immobility.

She has found that she can combat that feeling by struggling to get up and move around a bit.

I charged off on a search this morning with the internet of all knowledge and found this timely article at Parkinsonsdisease.net [https://parkinsonsdisease.net/living/leg-pain].

...four types of leg pain in PD.

First type of leg pain is central pain

This pain is described as constant burning sensation with occasional burst of sharp pain. As it was in my case, this pain is commonly exacerbated by cold and by light touch. I could not stand the sheets to touch my skin and being in a cold room sent my pain through the roof. This type is usually bilateral but it may start on the side where other Parkinson's symptoms begin. For me, it was the leg where my rest tremor began.

Second type of leg pain is caused by dystonia

When related to levodopa, it usually occurs as a wearing off but can also occur at peak dose. In most cases this leg pain is unilateral and has direct correlation to medication intake. When pain is due to dystonia, it is more common in early morning. This type of leg pain is usually accompanied by toes curling and foot abnormally posturing.

Third type of leg pain is musculoskeletal

Musculoskeletal pain occurs due to rigidity, abnormal posturing, and lack of mobility leading to pain in the legs. It may also affect the joint like the hip or knee. This pain is usually more pronounced on the more affected side. It can be localized or widespread and also can be sudden.

Fourth type of leg pain is radicular pain

In this case, the pain is caused by compression of nerves in lumbar area which results in weakness, numbness and tingling, and loss of reflexes from buttocks to foot in a distribution of a nerve. It can be acute or chronic, and can be worse with standing and sitting, or better with laying down. Of note: in my experience many patients including myself have these symptoms not because of physically herniated disc but rather by the stretching of a nerve in the canal as it exists due to severe musculo-skeletal rigidity and abnormal posturing.

--Maria DeLeon

…

So there you are problem solved. But – there is always a but – I asked my wife of many years to read the referenced article and describe or discern as best she can the kind of pain she is feeling. Out comes a description of stabbing pain in her heals. In her words – like someone is stabbing pins into my foot.

Balance

More AHA Moments – Boats – Cheryl told me she is scared to be on her brother's boat.

Recently Cheryl's youngest brother invited her and the rest of her living clan and clan-in-laws for an evening ride on his pontoon boat that he moors in a small man made lake near his home in southern Indiana. I am always on the hunt for things to do with her that let her socialize a bit out of and away from our little condominium living situation.

Since Ken's text message came to me on the family text chat, I told her what he proposed. Cheryl responded with, "I will think about it." This is a phrase that she learned from her mother as a small child and she has used throughout our fifty years of marriage and many times during our child rearing years. Roughly translated it means "NO" or "no thank you." But being the polite person that she is, she does not want to hurt anyone's feelings, she rarely says no directly. (She also learned this from her mom.)

Cheryl has a lot of her mother's traits. She does not want to put anyone out. She does not want to offend anyone. She can be angry with me as could her mother when she thinks that is appropriate, as when I am being pushy. She does not want anyone to stifle their good time by worrying about her welfare. She is okay with isolating herself to (her perception) benefit others. She enjoys the presence of small children even if the small children are unsatisfied and complaining about it. She enjoys the presence of big children and wants to be a part of their life even if the big children are uninterested in letting her in. She likes big family gatherings.

Most recently she has a new special Parkinson's patient walker to help her move around with steadiness. After her appointment with her MDS neurologist on her birthday several days ago, I ordered this for her. In the picture is her new U-Step. I should have gained my AHA here since I just ordered this over the phone three days ago. (I am buying her a stabilized walker and suggesting we go on a boat that will wobble every time someone moves.)

U-Step walkers are designed specifically for folks with PD to give them a strong base to walk with and against

But, getting back on track, she said to me that she is scared to be on Ken's boat. That is the first time she has ever expressed that to me.

AHA MOMENT – Occasionally these pop up and I cannot always understand her needs. Prescience is not a strong trait of mine. But imagine for a minute, here is a person with balance issues and I am promoting going on to a less stable surface than she is used to. She can lose her balance and fall backwards when changing positions in our living room. Our building is built on a slab. It is hard to get a more stable surface. AHA (you moron).

Ken caught on pretty quick and proposed dinner tonight on the deck at Willie's restaurant next to the puddle (his term for the man made lake.) Tonight is anything goes pizza Tuesday. Willie's fits into the anything goes part of pizza Tuesday.

We will go tonight and take the new walker for practice and hopefully greater stability. *Carpe Diem.*

Once in a while the road seems straight even when it is not. – this is from a blog post in May of 2022.

I get Lots of Newsletters

This one – The Criminal Intent of Parkinson's jumped into my email from Parkinsonsdisease.net. The writer Dan Glass makes a great point. The premise of Parkinson's will not kill you but you will die with it – is the perfect example of a distinction without a difference. He uses funnier tongue-in-cheek language than me.

FALLS ARE SCARY
Falls can occur anywhere and for any reason to anyone but parkies struggle with balancing; those tiny muscle motions that keep our center of gravity over our feet and heels. Parkies with dementia struggle to remember and use the techniques taught by the physical therapists.

For me as care partner, I am guilty of getting overly upset and excited when I watch Cheryl move around without her walker in our condo. We have a standard looking walking frame for use inside our house. She is using it more but learning is individual and until she wants to do it exclusively or feels wobbly enough, it is not habit and I will have to gently nudge and remind her. Her retort is often, you are always telling me what to do. I guess I am. I fear for her safety. We have a U Step walker for when we leave and go anywhere else. She is used to having it with her but sometimes she will walk around it to get to the garage and into the car. I give her a reminder nudge.

She fell two times this week. I hope this is not a omen. Both in the bedroom doing various activities associated with daily living. The first time our niece Natalie was here cleaning and I was in the bedroom collecting towels for the Wednesday laundry towel load. My perception is that Cheryl was backing away from the dresser after getting something from a drawer. She passed behind me and landed on the floor to my right. As I watched she bent her knees and collapsed on the floor.

I showed Natalie how to help her up by getting a wooden chair to place near her and hold on to stabilize the chair. Cheryl knows how to get up. She maneuvers to get her strong side (right) under her and then pulls on the chair. Sometimes she sits on the chair for a bit to rest.

The second fall happened while she was folding shirts on the bed a couple days later. I had dumped the laundry basket onto the bed and she became interested in folding the laundry. Fortuitously she fell onto the bed sort of face first and did not bend her glasses.

PNEUMONIA

Aspirational pneumonia is something that I worry about with Cheryl but her cough reflex seems strong for now. I listen to her when she coughs. It does not seem deep or struggled. She does seem to be drooling more.

ANGST

Coming from the care partner point of view raising tension between cared for person and care partner person seems at best counter productive. Sometimes saying, "Let me know if I can help" is more calming and useful than barging in to take over the situation. When I think about events that have occurred along the path of this journey with parkinson I tell myself that over and over. Many times I listen to myself. It is easy to carpe the angst of some situation and slip into know-it-all pedantic care giver mode. (Lately i have been catching myself and stopping mid-lecture.)

And doing the best you can to continue with a life not driven by Parkinson is hard work. There is extra laundry. There is extra equipment. There is extra travel time. There is extra time associated with any social event. There is disrupted sleep associated with any specific morning time event. There is menu confusion. There is mental confusion. There is resistance to help sometimes. Nevertheless, as much as you are able to do it, live life.

Carpe Diem. *From my blog – Oct. 29, 2022*

Constipation

Bowel habits are annoying enough with old age. Parkinson merely makes it worse. But it can be bad news for a PD sufferer. Hold your nose, do not be embarrassed and ask about poop.

From a story further on: About poop; constipation is, in addition to a problem with those who do not eat enough plant material and soluble fiber, a common dilemma with Parkinson's patients. Once a PD sufferer has a completely backed up system other problems arise. The most common is nausea for severe constipation. Simply being uninterested in food and eating very little is also common. Many cannot discuss poop without giggling. Go ahead, we do.

I make daily notes about bowel habits.

Insomnia

Brought on by the treatment chemicals which can cause constipation but more importantly can cause a whole lot of other issues. For example, the care partner can turn into Mr. Cranky-pants. Because everyone is tired stupid meaningless argument can ensue. To counteract that I bought a new bed which puts us on different mattresses but in the same room.

Others that I know about have separate sleeping arrangements. Do whatever works. Sleep is important.

In time we discovered that one of the meds she was taking right before bedtime would often cause her to fidget with dyskinesia and she could not settle and sleep until that went away. We reduced her Sinemet CR to one tablet and almost immediately she began to sleep through the night.

Why is Slumber so Hard to Achieve?

(October 18, 2021)

The ageless question that I ask myself. Why does she not sleep?

Tuesday – dinner with friends; A completely sleepless night afterward.

Wednesday — nothing special about it, just Wednesday. A totally restful night. She didn't move when I got up several times.

Thursday — Exercise class as normal. Overnight a couple odd things; teeth brushing at 2AM and Noxema face cleaning (I said not church today) she came back to bed. Leg pain — half in and out of bed at 5AM.

Friday was slow moving. Overnight she slept through although she was awake when I came to bed after reading (11:30PM). This morning for the first time she leaked. She was totally asleep when I got her pills at 7AM. She didn't awaken for her bladder. She did not act upset about it.

Saturday overnight she slept peacefully. I awakened her at 3AM or so to use the toilet. She easily fell back asleep. She was sleeping deeply when I got her pills at 7AM. We went to church in the afternoon. She missed her 4PM meds in the confusion of preparing for church at 4:30PM. We had dinner with friends after church.

Sunday morning she was agitated and slept fitfully. She was fidgety in bed. In the morning she was worried about something. We went to my son's house to celebrate a birthday of one of the kiddos. Sunday night and early Monday morning she slept little. She was certain she had to prepare for the appointment with her neurologist at 3AM. She slept little if at all. I reminded her several times that her appointment is tomorrow Oct. 19. The information did not reassure her nor did it seem to stick with her even as she insisted she understood what I had told her.

Monday (today) she is still convinced she has a doctor appointment.

Carpe Diem…

Big New Bed Delivery and Nighttime Bliss

The big new bed was delivered yesterday. I thought that I had paid for the removal of the old mattress, box springs and the bed frame. Apparently there are tiny variations in the language of such agreements that I did not realize and was not privy to. When did furniture or any purchase like that become so complicated. Even though I asked the salesman – Can you guys remove the old bed? – what he checked off and I did not question was – "Removal mattress and box springs – $99.00." I forgot to ask about something that I knew nothing about. I should have asked, "And the old bed frame, headboard and foot board too?" He would have responded with, "That's an extra $50" to which I would have said okay. Once I am making the switch lets go for it. It served us well for fifty or so years. It is merely a bed. It has no particular sentimental value. I remember when we bought the whole bedroom set thinking to myself, that is a lot of money ($1600 in 1979). Beyond any of those thoughts it has served us well. It is time for it to go. It does not fit our Parkinson life.

The mattress and box springs left yesterday. The head board, foot board and frame assembly went into the garage. There is a lot of useless crap in the garage, like, I suppose, everyone's garage. On another day I will rid myself of useless crap so there is more space in the garage. I will probably not paint anything in the condo on my own so why am I keeping old paint brushes? I also have an electric hedge trimmer. We live in a condo complex that although it is small we pay to have mowed and landscaped and trimmed. Useless crap it is.

Alas, we were probably the last delivery of the day. The young men were on the way out when I asked lets see how you left it. I asked them to move the bed about a foot closer to the doorway of the bedroom so that it was basically in the same place as the old bed. they did as asked. The delivery included a sheet set and I had purchased a set of mattress covers from Amazon as well as a quilt and shame set and blanket. The install team left me with a queen size mattress protector which I was not expecting but again, had I realized it was coming, I could have checked that the correct thing was delivered. I did not check that fact. The queen size mattress protector still sets on the dining room table awaiting the delivery truck to bring to correct item (which is probably not on anyone's delivery list for today.) I am waiting to see how this all works out.

I am not perfect either! I ordered the correct size blanket from Amazon but I incorrectly ordered a queen size quilt. Woe is me. Amazon now uses Wholefoods Market for returns. There is one about two miles from me. It was a painless activity. Perhaps I will return to shop there. It is an alternative to Kroger which was there when the building was first put up and then got mired in some developer default controversy about ten years ago. Kroger moved out. The building was eventually completed. I do not know if the crane operator was ever paid. The crane stood idle along the highway for about a year while everyone traded paper and shouted at each other in court. Now it is where I return my oopsios to Amazon and there is a store that sells stuff to store stuff in. America has a lot of stuff. (Sorry I digressed.)

The first night was wonderful. Cheryl did awaken me to help her in the middle of the night but that was after she had gotten up to go to the toilet. I did not feel her get up.

After I got her up at 7 am for her first meds, she fell asleep deeply until I awakened her at 8:45 am. Bliss.

And Last Night was Bliss (Again)

The ups and downs of this Parkinson thing do not seem to allow for planning, comfort and looking-forward-to-ishness. I imagine it is the biggest headache we care partners have to deal with day to day.

In addition to the fact that Cheryl can be great one moment and in the next she can be off in the weeds punding or hunting around for something that does not exist or merely worrying about something that is days into the future, she sleeps fine several days in a row and then one night is up. If one does not have Parkinson one can still have sleepless nights occasionally. Parkinson merely makes it more annoying. But, holy cow, it can be really annoying and not only for the Parkinson person.

The previous night was miserable. She did not sleep until about 3 am. Last night she laid down at 11 pm and did not move from that position until 7 am when the LOUD AND ANNOYING alarm clock went off to signal TIME FOR MEDICINE. That is what it displays in two inch high bright green letters after it raises its brightness level so that it is visible on the moon.

I got her the meds. She took them and laid back down for a bit to allow them to work. I put the Kleenex box in front of the message to the lunar astronauts. I felt rested.

I went to turn on the "news" and was shocked to learn that there were sexual hi-jinks going on within the Southern Baptist Convention. Hoping for more news about the Pirates of the Caribbean star Johnny Depp and getting instead the fact that Hunter Biden was, as a husband, a stinker as told in a new tell-all memoir by his ex-wife, I turned it off to do the Wordle. Ho hum.

She got up a little later and put the big new bed back together.

We are up at the regular time with no extra laundry today.

Life is good. Carpe Diem.

An Update about beds and sleeping and sleep;

Not everything can be perfect. Although she and I sleep much better generally, I decided that sleep is more important than the 7 am meds dose. I have turned off the 7 am alarm.

Orthostatic Hypotension

The eventual fix for this is a drug called midodrine. It raises blood pressure by squeezing the tubing.

Fainting

Every morning at 7AM the extremely LOUD, BRIGHT AND ANNOYING alarm clock sounds its happy tune to remind us that it is time for Cheryl's first dose of various meds. My job is to get up and find them. I get a glass of water and bring them back to the bathroom. All of this disturbance usually awakens Cheryl. I help her get up and shuffle into the bathroom to the toilet and then to the counter to take her meds.

Her fingers may not be working well in the right-after-get-up time. At 7AM and a little, she dropped one on the floor. I got her to take the rest of her meds and eased her back to bed. I laid down too after finding that the little white pill she dropped was to combat her orthostatic hypotension which is low blood pressure associated with Parkinson disease. I put this pill with her vitamins that she took later while eating breakfast.

She takes midodrine to combat the hypotension. Generally it seems to work. This morning when she took it separate from her other meds but with her vitamins and shredded wheat, she became lightheaded and fainty feeling. In the past when this was a major symptom of hers, she would faint at the breakfast table. She rarely felt faint as she changed from sitting to standing which is were this symptom typically presents.

This morning she fainted while I was talking to her. She was looking gray in the face at the time. I helped her to the floor and propped her legs up on a chair. I sat on the floor with her for a bit until she felt like she could sit up. I outweigh Cheryl by about a hundred pounds or so and to me she feels pretty light. I also forget that we are the same age and that means neither of use is twenty-two anymore. Nevertheless I help her up by positioning a chair nearby and she pulls herself up or I get behind her and lift her straight up with my legs. I probably should not lift her but she really does not weigh much in my mind.

While writing about these little happenstances in our life with PD I run across a world of information about what to do and who to call.

It has been awhile since Cheryl fainted while eating breakfast. A couple years ago it was sort of common and occurred maybe once every other week or so. It was so commonplace that I staged a pillow from our couch in one of the kitchen chairs to put under her head for a bit while she was laying on the kitchen floor recovering. Thinking back on it, it crept into our lives so gradually that the two old people living this Parkinson life thought little of it other than, oh crap another new thing to deal with.

A casual mention in conversation to the medical team in a visit a couple years ago caused Maureen to give me the "stink" eye look which said to me, when were you going to mention this? I realized fainting is not a good thing or even a thing that we should merely deal with over time. She gave Cheryl a prescription for midodrine and instructions to take two when you get up and two more during the day spread out. Later this was adjusted to one in the morning, one mid-day, one no later than three hours before bedtime. I now had a use for all seven boxes of our meds organizer.

I have started a little log of anomalous activities and the surrounding circumstances. The doctors and nurses are not looking at Cheryl every day. That is on me.

Kinesia

A general secretive medical term that merely means movement. It is not typically written by itself. Dyskinesia for example is impaired movement or put another way, disappointing movements, unsatisfactory movements.

The musculo-skeletal system of the human body is an amazing accomplishment of evolution. And like all servo systems used in industry has an input (brain command) an output (muscle actuator) and a feedback (kinesthetic sense). To those of you who have no Parkinson or other malady, close your eyes and touch your nose. If you did it flawlessly, your kinesthetic sense is working correctly. In Parkinson's patients this sense is interfered with and does not work correctly.

Tremor
Shaky movements

rigidity
Unable to move

bradykinesia
slow movement

postural instability
balance problems

Dementia

Apathy and Living

Is she apathetic about life? As we move forward it seems to me that she cares less about day to day activities. She seems to recede into her own thoughts but not as a prevailing occupation. I think of it as apathy-not-quite. When she gets in this mode it's often temporary. She is tired from some activity.

Specifically activities like taking a shower, getting cleaned up,   physical therapy sessions or exercise classes are obviously tiring for a PD sufferer. Something as easy as thinking about what is next seems to tire her out also. It like a temporary apathy. Procrastination?

It starts with, " I don't think I can go to… exercise class, church, physical therapy…" Admittedly it takes a lot for anyone to be motivated to exercise. It was not a big part of our lives when we were younger. Neither of us were sports buffs. My main sport riding my bike. There is a solitude to doing that which I am unwilling to give up or share. As her care partner, it is frustrating for me that she cannot observe how much she is helped by exercise and her PT sessions. She seems to not remember. It seems like she is going merely because I am taking her there.

When Cheryl gets in this mode (mood?), I turn the corner to something else. I am resistant to letting her go on and isolate herself in her little office area thinking, punding and organizing. I take her out. Anywhere works as long as it is out of our condo.

Yesterday I took her one of our local county parks that we have not visited for a long time. Afterward we went for ice cream at a nearby Dairy Queen. I had planned to make dinner at home but she suggested we find barbecue somewhere. This being an odd suggestion because it seems to upset her stomach often and she says never again later in the evening. We did not find the barbecue place to be amenable to folks with mobility issues so we landed at one of our old favorites and ordered something different than we usually get so the newness was preserved. On the way home she thanked me for taking her to Lake Erie and she told me a story about when she was very young.

In the early days of her father running his own gas station which was a life long dream of his, he rarely took any vacation time. It seems one of his friends had a vacation cabin up near Lake Erie and not far from Port Clinton. There is a park nearby called East Harbor State Park. Our walk by the shore of a much smaller lake in the park much closer than Lake Erie must have taken her mentally back to her childhood and a very fond memory. We visited the same area a few years ago and visited East Harbor. She talked at length about the trip with her mom and dad. She thanked me for getting her there and back in the same day.

I started this writing and contemplating apathy, but maybe it is projection (mine) apathy? Or predictive apathy? Or apathy is the wrong word? (indifference? passivity?) Or is it poor sleeping patterns? This morning she got up at quarter til ten which means that she was in bed for about eleven hours. She awakened this morning from the same position she fell into when she got in bed. On the previous evening she went to bed very late after midnight and slept very little. (As a result I slept little also.)

Is apathy and memory related? I wonder about ideas like this. Perhaps she cannot remember that she seemed to enjoy herself the last time we went there? Wherever there is.

When I finally teased Cheryl awake this morning, she opened her eyes and asked, “Is Mary Pat here?” An amusing opening question about the day. I smiled and told her, ” No Mary Pat is not here. I think you were dreaming about her.” I have no idea where the Mary Pat (a childhood and current) friend thought came from but she has talked to her a couple times over the past few weeks.

I encourage her to talk to her friends when she gets excited about some memory or misconceived thought. Many of them have had strange conversations with her about things. I used to be embarrassed for her and, at first, discouraged these phone calls which she often decides to do later in the evening. But as I thought about it I decided that it was not my place to absorb or accept or become embarrassed for her. Her friends know her state of mind. They are wonderful people and she is blessed to have them as life long friends.

Focus, cognitive abilities, caring, likes and dislikes are all related to memory issues. Staying active no matter how small that activity is actually helps with cognitive issues.

Puzzles and Parkinson's

An update to the story — The bottom line of the puzzle has appeared out of the sorting process.

She has decided that she will work puzzles as a hobby and diversion. I bought her a 500 piece puzzle to do. To tell the tale properly I have to go back about two years. We were Christmas shopping for the grand kids. We had passed by some puzzles in Barnes & Noble. She remarked that there was a woman at Bridgeway Point a local assisted living facility where her mom had been living until she passed away the previous year. And that she would like to get one to try it. She thought it might be fun to do.

We bought a 500 piece puzzle with a busy image of cars and buildings and dark sky with stars. We brought it home and it sat in the corner where Santa stores stuff for wrapping. After Santa wrapped the presents for the grand kids the puzzle box remained there for two more years until this past covid infested January. The puzzle discussion came back. I knew exactly where it was because Santa had not moved it in two years of wrapping.

Oh good! There it is! Where can I do it? I remarked that she could do it on the dining room table. I did not think anyone would disturb it. Only we live here.

What if Zachary comes over? Well, I do not know.

Your cousin John had a special table to put his puzzles on. It folds up when he wants to put them away. I said I would look into it. Then I bought a special mat to puzzle on. It arrived about a week and a half ago. This is a slow motion activity. One day this past week I blew up the balloon that it rolls around while watching the birds attack the snow covered feeder.

It is useful and has outlines of various puzzle sizes. Never mind that her puzzle is 20 inches by 20 inches when complete and it does not have that size printed on it.

As she stared at the rectangles printed onto the mat we had long animated discussions about how to do it. She wanted to find the center most piece and build outward. I suggested that that would work but it will be easier to find the edge and corner pieces and work in but it was up to her. Whatever she thought was best for her to do, I said.

She has decided to initially separate the pieces into groups of her own design. Edge pieces in one pile, Red here in this pile, yellow in this pile and on. I need some plastic bowls with lids that fit. I tried to purge the kitchen cabinet of the leftover bowls that went through the dishwasher one to many times and were warped by the heat.

These are okay but the lids do not fit. I need the lids to fit. The mat is supposed to roll everything up I said. Yes, she said but I need some bowls with lids that fit until I roll the mat up. I am in the midst of hunting on Amazon for bowls with lids that fit. Looks like I can get these preloaded with cookies. That would be a real bonus.

It is interesting how a parkie mind works or doesn’t work. I am still waiting to see how the puzzle gets started.

So far we have two bowls, a box and a zip lock bag. The mat is rolled up nicely by itself.

Carpe Diem.

In the Morning

In the morning after she has had her meds and has had something to eat and has been up for a little bit, she seems like her old self for awhile. It’s different on different days but this day she is like her old self for an hour or two.

It is interesting and calming to me when it happens. We have little teasers in the morning. I ask her if she wants coffee. She says no. I don’t drink coffee. She used to drink tea but she has not for several months, maybe a couple years. But I always ask her still.

When we were still working for someone else it is how we started our day. She never drank coffee in any form. It was how I got through college and everyday since. I stopped using sugar in about 1974 or so as a protest against the sugar industry. I am able to remember when sugar was ten cents for a five pound bag. I have not seen five pound bags in our little IGA for some time.

Cheryl always drank tea. I have some year-old tea bags in the pantry. Occasionally I will drink tea. Iced tea in the summer is pretty good. Dad used to drink iced tea. I think that I drink iced tea in his memory.

These days Cheryl drinks orange juice with breakfast whatever breakfast may be. Nothing else is satisfactory for breakfast. No milk, no coffee, no tea only orange juice satisfies.

In the evening and on this particular evening she wants to go home. She seems to understand that she is home and somehow not home as I explain why all her pictures, papers and clothes are here. She will say, yes but I want to go home. My heart sinks when she says this. It used to make me panicky. There is no answer. I explain that we are home already and we will sleep here. If she wants we can go home tomorrow. That is okay with her but sometimes we have to call her sister to tell her where we are overnight.

In the morning she had been so much like her old self. In the evening she is different, unsure of where we are, uncertain of who I am, and wants to go home. The ups and downs and general upheaval in the same twelve hours or so of wakefulness is remarkable. Parkinson is scary stuff. (Some would say "shit" but I will not.)

> *…And whether or not it is clear to you, no doubt the universe is unfolding as it should. Therefore be at peace with God, whatever you conceive Him to be. And whatever your labors and aspirations, in the noisy confusion of life, keep peace in your soul. With all its sham, drudgery and broken dreams, it is still a beautiful world. Be cheerful. Strive to be happy.*

– Desiderata by Max Ehrmann

I am not convinced, Max.

Carpe Diem.

(From a blog entry in November, 2022)

Black Friday

This is a term associated with the Friday after Thanksgiving Day. (2022) We had been at Anna's house. Anna hosted. Almost everyone was there. Cheryl sat at the end of the table near Anna. Anna read a wonderful prayer. I sat at the other end of the table near Scott and Gavin. A great meal surrounded by family was enjoyed by everyone.

Thanksgiving Blessings

Lord, as we bow our heads to pray,
We celebrate Thanksgiving Day.
Help us have the right attitude,
As we turn to you in gratitude.

Thank you for our festive mood;
Thank you, Lord, for this good food;
Thanks for blessings great and small;
Thank you, thank you for it all.

By Joanna Fuchs
Poemsource.com

Today – black Friday – Cheryl was a little down this morning after breakfast. She talked about not understanding what was going on about her yesterday. (She did not remember that she had forgotten being there last night as we went to bed and I talked about the meal and conversation at Anna's house.) She talked about "losing her mind". She talked about her granddaughters who were sitting all around her not understanding the surroundings. We had another moment were we sat for a minute to recognize the changes in her memory and cognition. (I am losing her more and more and she recognizes that and it makes us both sad.)

Thank you Lord for the moments we both still have. Even if we cannot remember.

How to Cope With Capgras Syndrome

This syndrome was first documented by a French doctor. It manifests by the dementia patient believing (delusional) that a person is someone else or a thing or object is something else. In Cheryl's case she thinks that I am not her husband. She might say – the other Paul or that guy that brings the pills. Late in the evening Cheryl will want to "go home" when she has merely been in the other room for awhile.

In the case of Capgras syndrome, a person believes that a familiar person or place has been replaced by an exact replica of the original. **It's common for those with Capgras syndrome to believe that a loved one (such as a spouse or child), home, or animal is an impostor.**

If a loved one develops Capgras syndrome, it can be disturbing or upsetting for all involved. The delusions that accompany this condition are frightening for the person experiencing them, but it's often just as unsettling for the person thought to be an impostor **(especially if the person with Capgras is a parent or spouse).**

To cope with this condition and help your loved one, consider the following tips:

- **First, try your best to change the topic by playing music or focusing on a TV show, photos, or a pet.**
- **Avoid arguing or escalating the situation.**
- **If possible, allow another caregiver to take over when an episode is occurring. Alternatively, leave the room for 10 minutes if it is safe to do so and return with a happy greeting.**
- **Use a soothing voice and maintain a calm presence.**

Capgras syndrome is a condition that sometimes accompanies dementia, such as Alzheimer's disease or Lewy Body Dementia. If your loved one is struggling with symptoms of LBD, including Capgras syndrome, you may be feeling overwhelmed or unsure of how to help. When you need to find local resources in your area or simply reach out to someone who understands, our team is here to help. Please feel free to call our helpline any day of the week at 833-LBDLINE.

from https://lewybodyresourcecenter.org/what-you-need-to-know-about-capgras-syndrome/

I can tell you from personal experience that it is scary stuff and hard to get Cheryl to believe otherwise. She usually experiences this behavior in the late afternoon and evening but it can occur early morning also.

Jan 22, 2023

When I got up in the morning I noticed it had snowed some and the snow was continuing to fall. Helped her to get up at about 9AM and we talked about the snow and anything that we had planned was off for the day.

For much of the afternoon she had been "organizing her office". I checked on her two or three times during the evening and watched some TV. She was uninterested and remained in her office organizing. She remarked that I should let her know when I wanted to leave and I told her the weather was an obstacle. Several times this came up and I was able to bring her back to "here" by leading her through her fading memory of the day. – we got up here, we had breakfast here, it had snowed so we did not leave here, Jan came for dinner, step by step until she acknowledged each piece of the days events. (So, we are still here.)

Calm seems to be the best advice.

Perhaps if she starts down the road of thinking she is elsewhere I need to keep track of her journey and steer her back to "here" more often. When she went to bed she was not confused about "where". She was confused and anxious about coming events. She got up to ask when church was tomorrow.

--- not really Capgras but another feature of not knowing what the calendar means.

Recurring Themes

There are days, and this may be one of them, when I wish for Cheryl's physical Parkinson's symptoms to be worse and her mental Parkinson to be less. She actually moves quite well with the C/L in her system during the day. If in the middle of the night she might get up to toilet once or twice she moves pretty well then too. She might be slow and slightly disoriented but at 3 AM I am too.
Late Autumn and Winter is the worst for her mentally. Last evening she stayed up very late; frantically organizing and reorganizing her papers and cards in her office. She eventually allowed me to help her to bed about 11:30 PM. I heard the clock strike midnight before she succumbed to sleep. She had been talking gibberish about the kids.

FIVE REPETITIVE THEMES

She is often confused as to who I am. I am that other Paul. I am Dad (as I was last night encouraging her to get rest before our big outing with Marilyn.) Some times I am Scott but if not she will ask, "Did Scott go home? Or, Is Scott here?" Some of this is simply aphasia and she cannot find a name in her head. (Me too, occasionally.) If I cause stress in her by insisting on something she will be very anxious about me being around. Insisting is always a bad idea but I often forget that. I try to hedge and let her decide she wants to – go to bed, eat dinner, have a cookie, have cereal for breakfast, etc. Often that works, often it does not. It can be frustrating when you are also tired.

"I want to go home now." – She believes for a time often late at night that she is not home and wants to go home. Sometimes this delusion is overpowering and I help her find shoes and a coat and I drive her around a four mile circle and home. I reinforce the we are home thought by saying plainly, "we're home now. I'm glad to be here finally." That will reset her brain and she starts to think we are home.

Sometimes it works only partially and she thinks – wow, this is neat. How did they get all our stuff here so fast?

Recently she has asked how we will get all our stuff home? Do we need to get some movers? I merely replied yes, I will call them tomorrow and set it up. — I wonder how long the "I will take care of that tomorrow" ploy will last. For now it does. She has not yet asked when I was going to call the movers in the morning while I am organizing breakfast.

"We are in Detroit" When Cheryl went to high school she was following the prescribed path to become a Franciscan nun. I met her originally in the summer between her junior and senior years in high school. When she was a freshman, a teacher she had realized she may have some potential in English or journalism and arranged for Cheryl and a couple of her classmates to attend a journalism workshop in Detroit for a couple weeks between her first and second years in high school. It made a deep impression on her. In many ways, when she talks about it, it was as though she traveled to a foreign land. And she thoroughly enjoyed every aspect of it.

Her favorite TV show and the only one she really watches is a show called Bob (hearts) Abishola which is set in Detroit. Watching the the show, she will tell me stories about Detroit but mostly I think she looks at the screen because some views will spark a memory.

"When are we going home?" Is her theme some evenings when she is sure we are in Detroit. I did not realize at first where she thought we were. I discovered this later through conversation. — I can respond, "We are staying here tonight and going home in the morning. Is that okay with you? It is late and would rather drive home in the morning." Most times traveling along with this theme she responds with, "Yes that is a good ideas. We should rest first." Once in awhile the Detroit delusion lingers until morning. It is often gone at breakfast.

It is time for office work — is usually a physical activity. In our second bedroom that became her office when we bought this condo she will spend time organizing. Or doing nothing. It is her version of punding. If she starts doing it at 9 or 10 PM there is no easy fix to getting her to be interested in sleep even when it is obvious to me that she is very tired. She takes a prescription to help her sleep as well as melatonin to help her fall asleep but her will is strong when she decides to – get this stuff organized. It breaks my heart to see her do this mindless activity. Last night I sat with her because the later she stays up the wobblier she gets but her confused mind will not let her see this in herself. In her brain she is a 35-year-old computer database analyst and the deadline is tomorrow.

These behaviors generally occur late in the evening. I sometimes succeed in not being Mr. Cranky Pants. This part of His plan sucks for sure. It is hard to be calm when the Plan has dumped on you and the previous night was smooth and uneventful.

Whiskey Tango Foxtrot comes to mind.

Carpe Diem.

From a blog post – December ***2022***

Incontinence

Before you travel along with the thought that – oh hell another thing to deal with of Parkinson – be aware that there may be a real medical issue not of Parkinson. Urinary tract infections (UTI) manifest themselves differently in different bodies.

Cheryl had probably been dealing with a UTI for several weeks before I came to understand what might be going on and took her to the doctor.

Women are not open with their urination habits – even to their husband. Be observant.

Overnight

This was rarely a problem until we replaced the bed. Cheryl had been awaking me up when she got up to toilet in the middle of the night. I had been waking her up several times in the middle of the night as I got up to urinate several times with “old man's bladder.” Now the mattress is more comfy and she is sleeping on a different mattress than I am.

We use different more absorbent overnight underwear pants. They hold a lot of urine and rarely leak. We have washable pads that are strategically placed under the sleeper. Cheryl is taking one less Sinemet CR tab at bedtime which reduces her fidgety dyskinesia and this dose is given earlier in the evening so that the fidgety dyskinesia that still happens can abate a little before sleeping.

She sleeps sounder. I imagine that in her dreams she gets up to toilet. Before the big new bed arrived it often seemed to me that she was dreaming when I helped her in the bathroom over night. Perhaps she was and now she is less active overnight.

Once in a while I have extra laundry in the morning but overall it is worth it to get a good nights rest. The extra laundry doe not seem an insurmountable task when weighed against a good rest period.

And, most of the time, she does not produce enough to leak.

Daytime

As we moved through our journey down the road of Parkinson, she has become incontinent during the day. It takes the form of not being able to sense a full bladder. Little dribbles will stain her pad in her underpants. (One of her meds stains her urine to a brilliant orange-red color.) She thought that she had started menstruating again even though that has not happened for twenty years or so.

… in retrospect, probably a manifestation of a UTI.

Both

In the morning when I help her up and she sits on the toilet, as I remove her overnight protection and dispose of it, I encourage her to empty her bladder. She is not always able to control that action but it may also be that she has just done that in her overnight protection.

During the day it seems that she may notice that her bladder needs to be emptied but she is sitting in a chair. Sit-to-stand is no longer a natural motion for her. She will bounce a bit to help her get out of the chair. This bouncing motion may help squeeze and dribble urine from her bladder.

So far there does not seem to be a good solution to incontinence other than absorbent protection.

Sun-downer's syndrome

When this shows up it is hard to embrace it. It is much easier to rage against it. I often rage before I realize what I am doing. The following story might be helpful to understand what is going on in a parkie's head. Parkinson can affect thinking.

A way to ameliorate a sundowner episode is to raise the light level and talk softly and confidently with your parkie. It does not work every time but it does tend to calm any anxieties.

An August Evening

Rainy days in August produced sundowner's confusion and dementia. On this particular day it seems a bit worse.

Cheryl has had a particularly busy week. Two physical therapy visits and an exercise class happened this week. On Monday evening our HOA board had a meeting to discuss maintenance schedules and what new projects we could take on with the money on hand. Jane came across the hall and sat with Cheryl on our back porch while I attended. (Jane is a wonderful neighbor.)

On anything goes pizza Tuesday we had dinner with our neighbor Jane as usual and in addition our new upstairs neighbor Joe joined us. Joe moved into the front condo over the garage spaces. Much of getting to know you conversation happened. Cheryl knew of a woman which she attended high school with who had the same last name. Her name was Kathy. As it turned out she was Joe's younger sister.

Jane's husband used to play in several bands when he was still alive many years ago and Joe's last name was familiar to her also. As the story developed it became apparent that her husband John had played in a band with Joe's father.

It was a great getting-to-know-the-neighbor conversation. There were lots of memories for Joe and from Jane and Cheryl. When we got home Cheryl was exhausted.

Wednesday, I had arranged for my cousin-in-law, Linda, to come and take Cheryl to her physical therapy appointment. I went to visit the lab of a local community college program that I am still involved with. That facility is twenty minutes or so down the highway and I was gone for about two hours. We later met back up in a local diner for lunch.

Thursday it was my intention to attend a exercise-for-care-partners class at Parkinson Community Fitness after Cheryl's twelve pm exercise class. I had previously arranged for my daughter to pick up her mom so that Cheryl would not have to stay. I found out my class was canceled at the last minute so when Anna showed up we all went to lunch. Our grandson Max was with his mom and he showed off his new laptop he purchased for college. He will start in a couple weeks.

I had hoped to ride my bike for a bit so Anna and Max remained with Cheryl. Alas, the weather did not cooperate. As I entered our condo Anna was helping her mom sort coins. These had been residing on the dining room table for several days but the project was several weeks old. Cheryl found them back in her office a few days ago. Cheryl told her daughter that when they were finished they would give the coins to her dad. She used to help her dad roll coins from his gas station business many years ago.

Max was frustrated with his new laptop. The camera no longer worked. What ensued afterward was a chat via the internet with some Microsoft expert and ultimately a complete reload of the operating system. That seemed extreme to me but I am an old retired electrical guy whose been fooling around with systems, software and computers for fifty years or so. We are living in a new age now. Ultimately it was discovered that Lenovo had placed a privacy slider to cover the camera on the upper edge of the case. It was a mechanical failure or an operational one depending on who is characterizing the action.

On Friday I was still hoping to ride my bike and the weather was still not cooperating. Cindy came anyway And I went to get a haircut and run a few other errands. I returned about an hour later.

This whole week was generally gray and overcast. It was not gloomy like the wintertime but gray and rainy nevertheless. It is still rainy and poopy outside as I write this.

The rest of the day was filled with visions and stories of her family. She was looking for Scott. Later in the evening she told me a story about Easter eggs, coloring them and Mavis. She eventually called our daughter-in-law Mavis to ask about what her objection was to coloring Easter eggs.

Earlier in the evening she asked, “Where is Ken?” I told her that Ken was probably home but I was not sure. She should call him and talk to him. She did not take that suggestion.

It was a frustrating afternoon and evening for me. Later I realized after she had exhausted herself with a very busy sundowner episode that for the first time this week only I was here with her and she could relax and let all that out.

As she laid in the bed she asked me to make sure the kids all got home okay.

Showtime

When visiting doctors and family her demeanor changes completely. I imagine doctors are used to this. People change when visiting with professional people that they do not know personally. The is a reaction called White Coat syndrome that can raise one’s blood pressure when visiting a doctor. In a parkie the support group term is Showtime. Parkies are able to move better, think clearer and generally appear in greater shape than they are at home with their care partner.

Friday the Thirteenth

Friday the 13th comes on Friday this month. It is a little joke I have. An old boss of mine during my working career who is also a good friend used to make that comment when it was appropriate. It seemed to him that mystery problems would appear on Friday the 13th. Engineers love and hate mysteries.

A friend of Cheryl’s came to take her to lunch today.

I am waiting to see how it turns out. Barb is aware of Cheryl’s issues but we often only see her at church. Cheryl will have a chance to practice her “showtime” persona.

The lunch was great. Cheryl had a great time with a good friend and she brought home leftovers that she may or may not want to eat. The went to a Asian restaurant called the Blue Gibbon. Typically when we go to a Chinese or Asian restaurant she will order egg rolls. Nothing else for her, she only wants egg rolls which the restaurant people want to bring as an appetizer. No amount of English, American English, spoken to a person whose first language is not English can convey the meaning of “bring as her meal”.

The last time we went out to dinner at a Chinese restaurant (Uncle Yip’s) I ordered her egg rolls, some spring rolls for me and another dish that I like and I thought she would like. We had tea. The waiter brought the the egg rolls,spring rolls and asked if we needed more tea. Later he brought our shared dish. It worked out just fine. She was not embarrassed to eat ahead of me and she did eat a little of what I had ordered to share. The smart waiter brought us extra plates.

Uncle Yip's, by the way, is the closest thing to actual Chinese cuisine that I have found so far. I visited China about ten years ago for business. And the owner's and wait staff's first language is not English.

Carpe Diem.

Hallucinations

These are remarkably similar from PD one sufferer to the next. Cheryl describes girls and small children. She also makes reference occasionally to that woman who runs things here. That woman also occasionally sits or naps in out bay window-seat in our bedroom.

Parkinson's disease sucks March 25

Early Monday morning 3/25/19 Cheryl experienced hallucinations again. The hallway became a beach. Kids without faces were running around. The bed sheets became liquid like water. Ceiling tiles squiggly lines like snakes. She told me that I had on funny clothes, but I had on jeans and a shirt. *(she was very scared of her surroundings)*

She is sleeping now. It is 5:57AM. She just snored. She seems peaceful now.

This was written overnight at a hospital. Cheryl was having a bad reaction to her meds...

We Danced Last Night

Last evening after dinner we danced for a bit.

Cheryl was going through a bit of confusion as I put dinner on the table. She kept getting up to look for her deceased sister Janice. (She called her Janice instead of "Jan.") Eventually she was satisfied that Jan was not here to eat with us. She became interested in food and ate what I had cooked. (Chicken, noodles, green beans and broccoli)

I had put some music on the radio to play quietly while we were eating. Jimmy Buffet and "Margaritaville" came on when we were finished with the meal. I asked her if she wanted to dance. She said yes. We did.

For a few minutes we were young at a dance with Jimmy Buffet. Our dancing these days is more of a swaying-in-place but it is fun anyway.

A different time that we danced is in this picture. We were at a social gathering at Parkinson Community Fitness. Carpe Diem and seize every chance you get to dance.

From Lee Ann Womak:

I hope you never lose your sense of wonder,
You get your fill to eat but always keep that hunger,
May you never take one single breath for granted,
God forbid love ever leave you empty handed,
I hope you still feel small when you stand beside the ocean,
Whenever one door closes I hope one more opens,
Promise me that you'll give faith a fighting chance,
And when you get the choice to sit it out or dance.
I hope you dance... I hope you dance...
I hope you never fear those mountains in the distance,
Never settle for the path of least resistance,
Livin' might mean takin' chances, but they're worth takin',
Lovin' might be a mistake, but it's worth makin',
Don't let some Hell bent heart leave you bitter,
When you come close to sellin' out reconsider,
Give the heavens above more than just a passing glance,
And when you get the choice to sit it out or dance.
I hope you dance... I hope you dance.
I hope you dance... I hope you dance.
(Time is a wheel in constant motion always rolling us along,
Tell me who wants to look back on their years
And wonder where those years have gone.)
I hope you still feel small when you stand beside the ocean,
Whenever one door closes I hope one more opens,
Promise me that you'll give faith a fighting chance,
And when you get the choice to sit it out or dance.
Dance... I hope you dance.
I hope you dance... I hope you dance.
I hope you dance... I hope you dance.
(Time is a wheel in constant motion always rolling us along,
Tell me who wants to look back on their years
And wonder where those years have gone.)

Apparitions and Ghosts

Are we haunted?

Recently one of the older residents of our condo complex passed away suddenly from a cardiac arrest at dinner. This was very sad news indeed for her family and shocking news to our HOA and those who knew her.

Cheryl's version of Parkinson allows her to see apparitions, some would say hallucinations, but I think it is more than that. For example, there is an old picture from one of her mother's birthday parties on a piece of furniture near our dining table. In the background of this picture is a tiny image of our son and our daughter. My son's wife is also there with her back to the picture taker. I do not know who took the picture but fairly often when we sit at this table she will see and want to set a place for our children. To her the people in the photo are with us.

Today as we got into the car to go to exercise class, Cheryl described seeing a "blond or gray-haired woman" zipping down the hallway in a hurry. Cheryl said that she did not look around or wave as she went by. I asked a couple of questions about this person. How long was her hair? Short like yours? Or longer? Cheryl's description of the woman could have described the resident who had died a few days ago.

Marty was a sweet older woman who loved to garden. She was one of the original residents when this little group of condos as built about twenty-five years ago. She had problems with her back which kept her from doing as much gardening as she wanted but recently her son was living with her and taking care of some of that for her. I had solicited her help with talking to our landscape folks about adding some new plantings where there had been some damage by one of the other residents. This was a few days ago and the plan was going forward.

From Cheryl's description it could have been her in the hallway. Marty was HOA president until she gave it up to me. She was always checking on stuff. Making sure that it was just so. She was an excellent observer of the place. better than I am.

Could we be haunted?

Cheryl often describes to me a woman she sees in our condo sitting in the bay window seat of our bedroom. When she awakens in the morning she sees this person. She tells me that the woman in charge of the school… (Cheryl will add some description). I cannot resist pointing out that only we live here but perhaps like the actress in "Ghosts" only she can see them. Maybe I should emulate the husband ask more questions about who she sees. After all I am the chef these days.

We bought this condominium from the priest who happened to be the pastor of Marty's parish but he had bought it originally for his mother. She passed away before she ever moved in. Was she running a school?

I do not have any answers to any of this. What if the apparitions Cheryl sees are actual ghosts of people who were here before. Now they are faded out like unavailable options on a software interface menu?

Something to think about.

Memory loss

Who people are struggling which memory loss are encouraged by others who think they know how to help to use various devices. They are encouraged to make lists. They are encouraged to write things down. They are left to their own devices as to how to make sense of these devices later to get the memory back. Perhaps much is blather and bullshit.

The Birthday Book

This is such a good story I am unsure where to start. Had I been more alert to how Cheryl treated this book I could have foreseen the difficulties that eventually came to her and became much of my daily life. But seeing how she treats it now is unimportant and I flatter myself into believing I could helped her if I had been paying careful attention at the beginning.

About three years ago – certainly prepandemic – Cheryl was struggling with her birthday card organizational techniques. She had several old books of names. One of these was left to her when her mother had passed from this life to the next. When a new month was approaching she would collect these to her in her office in the evening to make a list of folks whose birthday was coming to buy cards.

When her mom was still alive she would take Elaine to the Dollar Store to buy cards to send out. She took this over in time for her mother and eventually kept it up after Elaine passed away. She did this, of course, in addition to her own birthday card list. So, one evening I noticed she had several old handwritten books that she was looking through to discover whose birthdays were coming next month.

She had entered much of this same information into an Access database that she had created during her working career to help her and her mom keep track of things in an organized and businesslike manner. Cheryl was an extremely organized business woman. The most disheartening thing for me to watch as this disease progresses is her loss of organization and control. If the disease was merely physical it would, I think, be easier to deal with.

Nevertheless I put on my engineering hat to help with different methods to enhance and at the same time add ease to the organization of the birthday cards. I a second career as a high school science teacher which never completely panned out, I discovered a wonderful organizational tool that teachers use and might very well be adaptable to Cheryl's needs. Teachers use a weekly planner to help with organizational tasks and as I discovered with my small experience, to keep track of how far behind you are with the course material. Usually these are dated with the year but at Staples I found a wonderful version that in addition to having only two days per page was lined and printed in a 8.5 by 11 format had no year printed. It could be a yearly calendar of birthdays, anniversaries and other information without concern for the year or day of the week.

The doomsday algorithm would give you the day of the week. Look it up. It is pretty neat.

She had been struggling with organizing the birthday cards. I suggested she use this yearly planner. In the store, she agreed that it could be a useful tool to organize the activity. I was proud of myself for finding such an elegant solution to her dilemma. Being the ever helpful hubby I produced from her Access data a list that I could put into Avery's online printing tool and produce the information for the dates that were known. New information would come along with use and could be added by hand as the years evolved.

Almost a good idea but my idea therefore NIMBY and NIH reared their ugly heads in unison. And I, not to be defeated, began to defend my method to a woman who spent her working career in computer databases and systems analysis, as she, slowly crept into memory loss, confusion and dementia. What a hoot! I completely and totally missed the AHA when it went by about two years ago.

How to help without helping? I continued for many months to reconsider and think about how to make the Big Black Book useful to her. In her old multi-book system she looked at a single page to discover who had a birthday that month. An index my engineering mind shouted at me. You forgot to make an index. I thought about that for awhile and realized that the planner was organized by month, not day-of-the-week, not year, only day of the month mattered. It was self indexing. I was at a loss as to how to fix her thoughts.

I quit concerning myself with instructing her on how to use it. I just rolled with her confusion.

Over time the preoccupation with getting out the birthday cards dissipated. Other thoughts of how to help her organize it left me. I became an observer. She always tells me, if I don't do it myself I can't improve. She is right. I am merely her aide.

Carpe Diem.

Delusional behavior

Something is not right. Delusional and confused behavior can take many forms. In Cheryl's case her mind centers in a couple areas. She is unsure of where she lives. She is unsure of who I (her husband) am. She is back in her childhood wondering where her brothers and sisters are. She does not know where we are in the calendar and believes various holidays are next week.

Why are we here?

I opened the papers – the local paper that is now part of the USA Today network for her. She still reads the obituaries. She has done this for our entire married life. And she enjoys the comics. She reads them all and works many of the puzzles in the same section. The Wall Street Journal for me. I still enjoy the business stories and cling to the hope of becoming rich in the markets. I may have started too late to achieve this but I am an optimist who is often disappointed by market outcomes.

We are both eating breakfast unusually early. Over time our get up time has kept later and later until eight am is pretty typical. Most mornings now I get up at seven am with the alarm and get Cheryl's first dose of the day. She takes them and goes back to bed for a bit. Today our breakfast discussion started with —

- Cheryl – Why are we here? When did we come here?
- Me – (uh, oh) We live here we moved here about four years ago. Do you not remember?
- Cheryl – No. Not really.
- Me – Does this not look like our house?
- Cheryl – Yes, I guess so. We live here? We're not going home?

My eyes well up here when I recall this conversation. It has been a few weeks but we have had it before. I am talking to a different person. She knows who I am but her anchor in reality is gone at this moment. Later her reality will be switched back on, I hope, but for now it is up to me to help her find her way back. It is the scariest thing that I have to do and I am at a loss as to how to help her. No amount of debate helps. Denial of her understanding merely makes her anxious and upset. Imagine that what you believe is upside down is right side up according to the person you trust most to tell you the truth. Are you loosing your mind?

A long discussion ensued. Within this discussion I gently tried to persuade her that this was our place and we did live here. For an hour or so it seemed that she believed me but was skeptical. Eventually she announced that she was tired and was going to lay down for a nap.

I Want to go Home

This "I'm not home" is recurring theme in Cheryl's head. She often asks "when are we going home?" I have a note about it in July, 2022. I try at first to answer this by saying that's good because we are already there. This sometimes works. Sometimes it merely makes her angry with me.

The conversation is confusing when we reach this point. I can say to her, okay put on some clothes and we will get some lunch and come home. So, how would you find clothes for you in a place where you did not live? This is the first confusion but she accepts the fact that she has all her clothes here without accepting the truth of "home". Even I am confused.

I wrote - later today, she is dressing now, we will go find some lunch somewhere and come home again. We did that and all was well afterward.

That afternoon she had physical therapy and she was tired afterward.

The Routines of Everyday Life

Routine tasks are big important things nowadays. As our journey progresses Cheryl needs more and more help with simple tasks. She also resists this help. It is a delicate balance of suggesting and helping and gentle steering. And there are days when I am unable to put up with the slow meandering behaviors of her Parkinson. I am usually apologetic and sorry afterward.

I sit down at this hiker's guide and ponder things.

Head and Hair Worries

Thinning hair

Cheryl has been worried for some time about her hair and the fact that it seems to be thinner as she ages.

Allison

Special shampoo

Special sauce for after shampoo

It Seems Counter-intuitive

From a Blog entry in September of 2022

Cheryl has some dementia which is a nuisance with her decision making process. Any attempt at speeding her up doesn't seem to work well. She merely gets angry and frustrated with her husband. And it is hard for her husband to not speed her up. That must be fifty-two years of helping getting in the way of care partnership.

This morning I tried to move her along without being pushy. Yes, I can be and have been pushy.

She wakened several times overnight to go to the toilet. I got up to help her once. So, when the seven am medication alarm went off, she ignored it. I got up to remove that annoyance from my ears and get her first dose of stuff for the day. When I returned her snoring indicated disinterest in arising for the day.

I laid back down to see if she would stir again. When I awakened it was eight am. I must have been tired also.

Eventually I left the bedroom to make coffee, get the papers and turn on the news to discover which part of California is on fire. An hour or so later I kissed her awake and she asked me when church started. I told her that she had exercise class at noon. I left to drink more coffee and to listen to the interesting fact that no toilets could be flushed in Mississippi. I returned for another gentle nudge and she got up.

I suggested scrambled eggs and toast for breakfast and she readily agreed. I continued with gentle nudges and quit concerning myself with whether she would be late for her class. She was not late.

The exercise classes she takes at Parkinson Community Fitness are a benefit to her so I make every attempt to get there on time but today I tried a not pushy technique. I call today's strategy "bump and run." I would engage her and nudge her thoughts and then leave. I came back a few minutes later for another bump and run. It worked and neither of us was upset when we left.

Carpe Diem.

One More Thing

There is always one more thing to do, one more chore to accomplish, just one more job. The unpaid but highly rewarding job of care partner is filled with unrelenting detail and a never ending series of little jobs. The list is long. New things are added often.

Take some time to reflect. Cheryl's creeping dementia does not allow her learn new things or compensating techniques easily. And she may not learn them at all. She might learn the reverse. Always be encouraging even as you as care partner become discouraged.

Carpe Diem

Enjoy the rest of it.

Whatever it may be.

Help where you can. Sometimes she will refuse the help. Help anyway.

Double Carpe Diem.

From September 2022

Exercise

Parkinson Community Fitness is a very special facility near us in Cincinnati. I take Cheryl there four days a week for various exercise classes.

From their annual report:

Our Mission:

To provide a dedicated space for Person's with Parkinson's (PWPs and related diseases) and their families to go for exercise, support and social events.

Our Purpose:

PCF will provide a solution to a long standing and often unspoken problem for those with Parkinson's Disease: A one-stop shop for PWPs where they can exercise while bringing back social interaction; sometimes lost in the PD journey. ; A non-judgmental place where PWPs can nourish their dignity.; A sanctuary out of the public eye and away from inadvertent glances.; A support system created by PCF staff members and volunteers.

This facility is very beneficial to Cheryl. We joined in October of 2019 after meeting a couple folks at the U. C. Health Symposium in August.

LSVT Big

A specific series of exercises for the parkie. – From their website:

LSVT BIG trains people with Parkinson disease (PD) to use their body more normally. People living with PD or other neurological conditions often move differently, with gestures and actions that become smaller and slower. They may have trouble with getting around, getting dressed and with other activities of daily living. LSVT BIG effectively trains improved movements for any activity, whether "small motor" tasks like buttoning a shirt or "large motor" tasks like getting up from sofa or chair or maintaining balance while walking. The treatment improves walking, self-care and other tasks by helping people "recalibrate" how they perceive their movements with what others actually see. It also teaches them how and when to apply extra effort to produce bigger motions – more like the movements of everyone around them.

Because LSVT BIG treatment is customized to each person's specific needs and goals, it can help regardless of the stage or severity of your condition. That said, the treatment may be most effective in early or middle stages of your condition, when you can both improve function and potentially slow further symptom progression. Beginning your work with LSVT BIG before you've noticed significant *problems with balance, mobility or posture will often lead to the best results, but it's never too late to start. LSVT BIG can produce significant improvements even for people facing considerable physical difficulties.*

Therapists are trained specifically to get the parkie to understand how to use their body and muscles normally. This of course is tricky when dementia enters the picture.

We met with a group of therapists in October of 2022 to investigate this for Cheryl. So far we are still waiting to her back.

And Loud

And for the parkie voice… Also from their website:

LSVT LOUD is an effective speech treatment for people with Parkinson's disease (PD) and other neurological conditions. *Named for Mrs. Lee Silverman (Lee Silverman Voice Treatment), a woman living with PD, it was developed by Dr. Lorraine Ramig and has been scientifically studied for over 25 years with support from the National Institute for Deafness and other Communication Disorders within the National Institutes of Health (NIH) and other funding organizations. LSVT LOUD trains people with PD to use their voice at a more normal loudness level while speaking at home, work, or in the community. Key to the treatment is helping people "recalibrate" their perceptions so they know how loud or soft they sound to other people and can feel comfortable using a stronger voice at a normal loudness level.*

While LSVT LOUD treatment has helped people in all stages of PD, the majority of research has been on those in moderate stages of the disease. *LSVT LOUD has also helped people with atypical parkinsonisms, such as progressive supranuclear palsy (PSP), and has recently shown promise for adults with speech issues arising from stroke or multiple sclerosis and children with cerebral palsy or Down syndrome. Beginning your work with LSVT LOUD before you've noticed significant problems with voice, speech and communication will often lead to the best results, but it's never too late to start. LSVT LOUD has the potential to produce significant improvements even for people facing considerable communication difficulties.*

As this disease progresses in Cheryl, I have noticed that she talks softer. We say WHAT? A lot to each other. I admit to being a soft talker as well.

Raising my voice to be heard is often interpreted by Cheryl as anger. It is usually frustration with not being heard. I am not convinced there is anything wrong with her hearing but her mind is often way off in the weeds somewhere.

Back in our younger years we could detect when we were talking to each other. As we travel the road of Parkinson, it is less obvious who is being talked to. In Cheryl's case sometimes she is talking to the little kids she sees in the evening. (If I ask her who she is talking to, she can become embarrassed.) If I realize what she is doing I will say, "Who do you see?" and she will tell me who it is. She may struggle with finding a name or she may be seeing and talking to one of the little "no-name" girls that go to school here.

I have learned that prefacing my remarks with Cheryl's name or Cheryl, do you… that it seems to bring her into whatever conversation I want to have. I do not always remember however and that is on me. So much of human communication and conversation is visual in addition to audible and with Parkinson and dementia that visuality is diminished. Words on paper can be meaningless. A sigh is interpreted as disappointment.

Biking

For me as care partner and not a particular fan of exercise classes, I like to ride a bike. It is a nothing special Townie 7D bike. It is a ride around town bike. It is not a trail bike. It is not a tour de France bike.

Why Ride?

A great poster

I ride to empty my head and relax. This poster captures how I feel riding my bike generally.

Lately however I have Cheryl on my mind I'm unable to assure myself that she is okay while I am away.

It distracts me from the Zen zone that I get in. Runners call it – runner's high. In my case it's bikers butt.

Getting to it can take several miles. But if get there it is all smiles inside your head.

There is a zone when you ride and a rhythm in your brain as you strain to listen to a podcast.

Or avoid the mom's with small ones who refuse to cooperate that day but are doing their best to rest little feet that are not as fleet as mom's are.

I ride the same circle and listen to whatever on my Bluetooth earbuds that did not come from Apple.

A book takes too long but a song or two or three is just right and Pandora tells me to buy their service with out ads for five bucks a month but with fifteen seconds of ads it is better than commercial TV and it is free.

If I want words about nothing or about something a Podcast is just right and a delight. It can be insightful if it is about something or frightful if it is about something else.

And eventually it is noise and I am in Zen zone and cone of self and the world is separate and indistinct.

It is a joy to ride with the wind at your back. It is like flying but slower.

Electra Townie 7D – cheap, efficient and fun.

This is my bike. I am not trying to get anywhere. It is just there to ride and hide for a bit from responsibility and duty when it calls.

Glamorous it is not but it is what I got in addition to bike tights and the rest of the kit to look fit.

Ten miles is typical and twenty miles is magical. And then the podcast is over.

It is sad but I am glad that for a bit I felt very fit in the zone.

Bobble-Head Biker

Children even grown ones, maybe especially grown ones can surprise you in the most unusual way. Today my daughter gave me a very special Father's day gift. Read on.

Bobble Head Biker Dad

Twas July the ninth a day like any other
Today was a thirty year celebration for Cheryl's brother.
In business he was for that time at that place,
only he like his father could keep up the pace.

But before we left to celebrate Dan's glee
My daughter Anna sent a text message to me!

Would I be home about two-ish? You see, she would stop by
A treat for me was in the offing. I wondered why.

No. Sadly I replied for Dan's party on our calendar did note
We have planned to visit from one to four to help him gloat
about a business that he tended for life with much pride
And hopefully soon he would into the sunset ride

Secretive was Anna with her clues and her hints
I imagined her baking and thought not of it since
When we returned from the celebration of Dan,
A gift bag on the dining room table did stand.

Happy Father's day it shouted with great joy!
Catch on I did not, Anna's secretive ploy.
Within was a box, its contents wrapped with care
It was obvious to me no baking was there

Instead was something that inspired me to write
this poorly worded rhyme, an iambic fight
Prose is more my love. To wax philosophic
Poetry and rhyme is for me catastrophic

But I gave it a go. And now I am through
Thank you Anna. You know I love you.
And on my desk near others, you know I will add
this wonderful addition of bobble-head biking DAD

Support Group

Joint Support

In 2018 Cheryl started her own support group at our parish church. (nativity-cincinnati.org) She did this after discovering that our pastor as well as several other parishioners had either Parkinson's disease or Parkinson-like disease. She felt the need for a place to collect and talk about symptoms, what works, what does not work and maybe pray a little.

She asked John Matre if he would help. His wife, Molly, had passed from this life about a year before but she had PD. Over time Cheryl was unable to organize the meetings. John stepped up when I asked him to help with that process. He is a great help with this group. John is a retired teacher and as such very organized with putting together discussion topics for the meeting. My job is mostly meeting announcement and administrative detail.

Eventually the Covid fiasco drove us from our meeting place in the church administration building. We asked and we moved our meeting to Parkinson Community Fitness on Kenwood road in Blue Ash Ohio. The PCF folks forward our meeting announcement to all their members. The following are a typical meeting announcement and notes (wrap up) from John.

– PD Meeting, June 20, 2022 Topics for Discussion/Wrap up

> Taken from Davis Phinney manual: “Every Victory Counts” ... For Care Partners ala What's the best way to approach difficult conversations with my person with Parkinson's or caregiver?
>
> I don't want to nag, so how do I encourage my person with Parkinson's without harping or nagging? Many of our caretakers go ahead and nag when necessary!?!? Lol
>
> How can I tell if I'm expecting too much/too little from my person with Parkinson's
>
> How can a Parkinson's care partner live well today?
>
> How can a Parkinson's care partner be loving and supportive but also honest about how they are
>
> feeling.

– PD Meeting, July 18, 2022 Topics for Discussion

> 1) How do you motivate, or cheer someone up who has Parkinson's disease?
>
> 2) What challenges does a person with Parkinson's disease face on a daily basis?
>
> 3) What is the importance of medication timing? What Strategies work for you?
>
> 4) Share 1 piece of information or a coping strategy that you wish someone had shared with you when you were first diagnosed?
>
> 5) How has Parkinson's Disease been a blessing?
>
> 6) What has been the most frustrating thing you've experienced since being diagnosed?
>
> 7) What are some lessons you have learned while living with Parkinson's Disease?

These topics will get a meeting started after we introduce any new meeting attendees. The conversations center around various difficulties that arise as a result of creeping mobility and mental issues. Occasionally care partners will disintegrate into complaint about their PD person but that is what it is all about. We learn from each other. There is no universal fix for PD.

Surrounded by Friends

In the Autumn of 2021, I found out through no fault of my own that we are surrounded by good friends willing to step up and help out with Cheryl's care.

I appreciate everyone's help whether it is a small thing or a big thing. Sometimes it is a phone call. Sometimes it is merely joining us for dinner after church. Sometimes it is taking the roll of care partner for a couple hours. Sometimes it is staying with mom while dad goes somewhere for an hour or a week. I love you all. Thanks so much for helping.

Cindy

Cheryl's cousin's wife Cindy began coming over to sit with Cheryl or take her to one of her exercise classes once a week for a couple hours. I am free to do whatever. (Thanks, Cindy.) These days in the warm summer Ohio air, I often go ride my bike somewhere. Cindy surprised me last Fall by asking me what I did for exercise after a discussion about Cheryl's exercise classes. One of Cheryl's instructors was a friend of Cindy's. Cindy spontaneously offered to come and be with Cheryl while I did something else other than care give. It took me several weeks to figure out what to do with my new found freedom and now I look forward to it.

Jane

Our next door neighbor, Jane, comes on Mondays typically to sit with Cheryl for a bit while I go ride my bike around somewhere. Cheryl sometimes walks across the hallway to visit with Jane. She is a good friend and close. Often Jane goes with us on "anything goes pizza Tuesday". She reacts to Cheryl's discussion much like Nancy does. Over the years Jane has had issues with her health and Cheryl's first thought is to see how Jane is doing. Jane has pointed out things to me that she notices about Cheryl and has suggested solutions for those without any judgement. (Thanks, Jane.)

Linda

My cousin's widow, Linda sits with Cheryl while I go do something else. Most recently I signed myself up for a caregiver's class to find out about other services that were available. Linda came over fairly early in the morning so that I could attend this class. I found the class itself very useful. It was primarily oriented towards care partner health and well-being. (Thanks, Linda.)

Mary Jo

A few months back Mary Jo sent this email to me to remind Cheryl (and me) of a commitment she had made during a chance meeting at our parish Lenten fish fry.

Prayer Partners for our Nativity First Communicants

to me

Paul,

Below is the email I sent to Cheryl. If you have any questions please let me know. I hope this isn't too much trouble for you. If it is, let me know and I'll find someone else. The last thing I want to do is add to your never ending list of things to do.

Mary Jo :)

P.S. I was thrilled that Cheryl remembered me! I would love to come over and visit with her some day and give you some time to yourself. Tuesdays and Thursdays are good for me. Please let me know how I can help. *… my bold letters*

Mary Jo :)

Hi, Cheryl!

It was so good to see you tonight at the Fish Fry! I feel like I have lost touch with so many people these last two years.

Thank you for volunteering to be a Prayer Partner for one of Nativity's First Communicants. The person you will be praying for is:

Lauren Miller

We ask that you keep Lauren in your prayers these weeks before First Communion which is Sunday, May 1, 2022 at 1:30 pm. Send her a note or a card this coming week letting her know that you are thinking of her and praying for her as she prepares to receive Jesus in the Eucharist. Then, send one more note or card as the special day gets closer. In these short notes you could also tell her something you remember about your First Communion day. If you have any questions, please send me an email or give me a call.

Again, thank you for offering to be a part of this important ministry. It's so important that these little people know that they are an important part of our Nativity Community and that we walk with them as they journey through their life of faith.

Peace,

Mary Jo

Nancy

Last evening we had dinner with Cheryl's sister Nancy. We have been doing this more and more. It is helpful to me in a couple ways that Nancy might not think about. Nancy, firstly, is not dealing with any dementia. Her conversation seems to go in a straight line. That fact by itself often provides relief to me. Over the course of my working career I traveled to other countries and many of these did not have English as their base language. It was always a great relief to hear American English from the people around you waiting for an airplane back to the states. Cheryl's mingled conversation is much like trying to make sense of a foreign language with little preparation.

The second thing is that when Nancy talks to Cheryl she is accepting of whatever Cheryl might say. Cheryl tells her about the children in our house, their sister Janice and other thoughts as they occur. Nancy does not correct or suggest anything different. Sometimes she will ask for clarification if Cheryl has mixed up names or dates. Cheryl recognizes that she does mix things up but she does not have the stress of keeping the story straight. That is stressful to her, saying the right thing; giving the right answer; not offending anyone. She learned those from her mother and they are deeply ingrained in her personality. When talking to Nancy she relaxes. (Thanks, Nancy.)

Family – Sons and Daughter

My son David and his wife Melissa have a wonderful patio and a big green backyard. Many times with little warning I have asked to come visit for a bit with Cheryl. Cheryl likes to visit her children and see how they are doing. Sitting on their patio in the sun brightens her mood. It gets us out of our little condo and does not require a lot of preparation by me. It is a sort of little day trip for her and I can chat with my son who is a fellow engineer.

They have always responded with yes. (One time they were out of town on a spontaneous getaway weekend.) Thanks, David and Melissa.

My son Scott sits with his mom while I go to my stock-club meeting once a month. (Thanks, Scott.) In 1984 several of us engineers decided to make ourselves rich by speculating in the stock market. We started meeting in March of that year. The markets have soared and ebbed. We languished through "black Friday". We bought gold mining companies. We sold gold mining companies. We drank a lot of beer discussing and criticizing corporate management. We have won big (ABBV) and lost big (F). Good friends and lots of beer with dinner in the back room of the bar makes for a fun evening. (Thanks again, Scott.)

I have also parked Cheryl at Scott and Mavis's house near us so that I could ride my new ebike around our old neighborhood. Cheryl could see Zachary – the newest grandchild – run around while I was riding. (Thanks, Zachary.)

My daughter Anna visit's with her mom and in the summertime when her high school is on break takes her mom to exercise class. Last summer Anna stayed with her mom for a week while I went to visit my sister on the west coast and we attended my nephew's wedding. Jeff and Stephanie have a new baby girl. (Thanks, Anna. See Anna's expose below.)

Allison

Allison comes once every six weeks or so to trim and shape Cheryl's hair. Before she started coming to our condo I took Cheryl to the Salon Named Desire every few weeks to have her hair cut. The salon is located on the second floor of an old building in the business district of the suburb of Pleasant Ridge.

Overtime it became harder and harder for Cheryl to negotiate the stairs. When Cheryl had foot surgery I asked her through the salon if she would be willing to come to our condo to cut Cheryl's hair. She did and as I discussed it with her she said she had several clients that she visited at home.

Cheryl's foot healed and we went back to me driving her to the salon but eventually it became an issue. We adapted and so did Allison. When she leaves I vacuum the large bathroom floor.

Jane's Organization

Cheryl has a wonderful bunch of friends with whom she used to play bridge.

Clementines

Kathy, Jeri, Kathy, and more is a great group of friends she has had since grade school.

Lunch with Rosie

Cheryl went to high school with Rosie. Rosie went on to become a Sister of St. Francis. Cheryl went to the prom with me and four years later we married.

Yesterday after many scheduling issues we hooked up for lunch. Cheryl was moving very slow that afternoon. Rosie moved very slow with her and very gently held her arm into the restaurant and over to the table. In conversation, Rosie, the quiet calm and gentle person that she is with her own health issues, gently took Cheryl down a memory lane of remembrances from their high school years to their current time.

I slowed a bit and observed. Slow and gentle were Rosie's movements, her companionship, her conversation. I learned something.

When we got home Cheryl rested for a bit.

I realized that Cheryl needs to go at her own pace. I always knew that she did but I did not always observe that pace or make myself slow to her pace. Cheryl's pace is principally Parkinson slow with occasion spurts of Parkinson fidget and sprinkled with Parkinson frantic and a little normal motion and conversation.

She did not seem really very tired or ready to go to bed at what I think of as her normal ordinary bed time of 9:30 – 10 PM. I tried to exercise what I had observed earlier in the day and suggested we play a card game or work a puzzle for a while. She said let's play Uno. We played with half the deck. She shuffled the cards and asked, Does everyone get seven? I said yes and she did not deal any extra players. Uno for those who do not know has a simple theme. Follow the color or follow the number. She could do that for about an hour or so. She began to notice on her own when she could not tell the difference between red and green. She declared herself tired about 11:30 PM and we got ready for bed. She slept soundly for several hours — all at her own pace.

Rosie taught me something. Let Cheryl set the pace. And if she is not around, think about letting God set the pace. Life is peaceful at Godspeed. Life at warp-speed requires quick reactions and having your shields up at all times.

Carpe Diem.

From a Blog entry in March 2022

Asking For Help

I wrote this letter to Cheryl's brothers and sisters in the Autumn of 2022. I could see the sun-downer's starting to happen earlier in the day. I have also noticed that when she is deep into that simply talking to one of her siblings or one of her children can help.

In May and the early part of June I sat in a class of sorts, more like a seminar on care partnering and keeping one's sanity. The seminar placed much emphasis on planning and executing time for yourself away from the constant activity of care giving. The seminar also placed emphasis on asking for specific help. I am writing this letter to you to describe some of those helps and ask that you find the time to do that for Cheryl.

Many of you read or have read my little blog about our life with Parkinson. It is a degenerative disease and it degeneration is agonizingly slow. But I notice little tiny differences as we move through it. I have always had a hard time asking for help in any form. This letter is an appeal to you to help your sister as she goes through her version of the Parkinson process. Some of these on this list will slow the mental decline that she is experiencing.

Below is a message and thoughts from a fellow blogger in New Zealand. I had no idea people far away were reading my little notes about us.

> *Acts of service, or perhaps my interpretation of it, is saying 'I love you' without saying it in words. While it is still lovely to hear those words the 'Acts of Service' are also powerful. They can be simple things like coming back into the bedroom after doing my morning exercises to find that – even half asleep – he has turned over and put the heat pump on to warm the room up for me. It is having him prepare dinner – even if it is just heating up some soup – when I need to sit down because of my current injury. It is putting the jug on and making a cup of tea for me while I shower. So many ways that we might do things for each other that might be seen just as a task to be done, but that if considered can be seen as that important 'I love you' without words.*
>
> *Next time someone does something for you, no matter how small, consider that they are not just carrying out a task, but doing so from the heart and showing that they care. As we move through the years on this Parkies journey, those Acts of Service may become more significant and those that we as people directly affected by this condition can do may seem less significant. However, if they are done with love, no matter whether large or small therein lies their significance.*
>
> *(2022) Kiwipommysue --My journey with Parkinsons*

So as I make this appeal to you select one of the small things on the next page and make it yours and your gift to your sister, you should know that I truly appreciate things that you have done. Cheryl needs all of you. As we enter into the Autumn and Winter months the days are darker and the sun light is less. This actually makes Cheryl's disease worse. Her head is a little goofier if that is possible.

- Call on the phone on a regular basis. Our home phone is 513 731 9272 and Cheryl's cell is 513 476 1586. She loves to talk to people on the phone. This is a hard one because she may struggle with finding words and names. You can play a guessing game but it is better to merely wait for her to find a word which could be a wrong one. (medical term is Aphasia)
- When you are talking to Cheryl in person or over the phone, engage with her and her stories even if you are certain she is wrong about something she has said. The idea is to keep her calm and unembarrassed. (exception – do not let her become fired up about some event that is not going to happen. She will worry that she has missed the event.)

- Talk about times in St. Bernard when you were kids. Picnics, visits to grandma and grandpa, Dad's gas station, whatever. Her childhood mind is pretty sharp. (sometimes these memories make her cry.)
- Visit often if you can. If I get a little warning I can make sure I have the correct soft drinks, etc. Early on when I was dating Cheryl, there was a lot of sitting around the kitchen table and talking about stuff. She likes that. (she misses these times.)
- Or bring lunch and talk about what is happening in your life. If you do this one please let me know ahead of time. I have signed her up for exercise class four days a week but nothing on Wednesday. It might be a late lunch.
- Come with us on "Anything goes Pizza Tuesday" for pizza and chatting. Text me and I will tell you where she has selected for pizza. (We have been doing this for 8 or 10 years now and it is a routine that she seems to enjoy. Our neighbors Jane and lately Joe Scheve have been coming with us.) – *Nancy has been doing this with us. Ken has once. Dan has twice.*
- Have family gatherings on a regular basis and take Cheryl with you to visit with others in your family. You all know Cheryl is keen on having some kind of family picnic, party, gathering. Her theme is always the Witzman family tree but what she is really after is the kids to meet and know their cousins even far distant cousins.
- Mail – snail mail – notes and cards to Cheryl, celebrating anything and everything. Halloween, Easter, birthday, anniversary, Christmas, Valentines Day. For years she adopted the whole birthday card thing and helped Elaine with her mailings. She gets very excited when she gets mail sent to her (or us.) It means so very much to her which is why it saddens me that she is no longer able to keep it up. *Ken and Jill sent Cheryl a Halloween card. She has another colleague that does this also.*

Any of these would be of great benefit to Cheryl. In many ways she has taken over your mom's roll in her mind. I think it comforts her to know that everyone everywhere is okay. She will ask me at night where you are, where our kids are.

Thanks in advance for your help.

So far – a couple Pizza Tuesday visits, a Halloween Card, and a discussion about family gatherings. No phone calls.

Blogging, Writing or Journaling

Try to do this for yourself if you are care-giving it helps to formulate your thoughts about the situation as it occurs. As I reread my old blog entries I tend to reteach myself things that I have learned and commented on in the blog. It is a meditation and a thought process.

The stories and vignettes included here in this guide were first published as a part of my journal and blog (AdjunctWizard.com) on WordPress.com. The separate file on this drive is called Hiker's Blog.

I also follow and communicate with several other bloggers who either have the disease and write about it or are living with and caregiving for some one with a chronic disease.

I got my second dose today

- March 13, 2021

I got my second dose today
hurrah, hurrah
We are ready to make hay
we are seriously gay
what else can I say
Pfizer was the brand on the bottle
or so they told me
How do I feel
I feel real
ready for the world to open again.
Life is short. I want to enjoy it
before it is over
One more time to smell the clover
And walk in the park
And shop in the mall
I want a do over
on life
Pandemonium is like ammonium
stinks
Blows like plutonium
boom

Peaks and Valleys

My first thought was – what a good description that is. It perfectly describes Parkinson life.

Flaming Lips ... Do You Realize

One, two, three, four
Do you realize
That you have the most beautiful face?
Do you realize
We're floating in space?
Do you realize
That happiness makes you cry?
Do you realize
That everyone you know someday will die?

And instead of saying all of your goodbyes
Let them know you realize that life goes fast
It's hard to make the good things last
You realize the sun doesn't go down
It's just an illusion caused by the world spinning round
Do you realize?
Ab-ah-ah

Do you realize
That everyone you know someday will die?
And instead of saying all of your goodbyes
Let them know you realize that life goes fast
It's hard to make the good things last
You realize the sun doesn't go down
It's just an illusion caused by the world spinning round
Do you realize
That you have the most beautiful face?
Do you realize?

Source: Musixmatch
Songwriters: Wayne Coyne / Michael Ivins / Steven Drozd / Dave Fridmann

Cheryl's Notes to Herself

As a way to combat her memory issues Cheryl began writing notes to herself in mid-2022. At first she called them her lists of things she had to accomplish. She writes them on anything and everything and I have obtained some of these and I include them here as she has written them. These are her little blog to herself.

- Written inside a blank thank you card: Maxwell's baptism. I believe it was taken on May 31, 1992 at the parish church they attended in Muncie, Indiana. Maxwell appears to be curious… but not at all afraid. What a lovely photo (The photo was not with this note.)
- Written inside another blank card – My name is Cheryl Weisgerber. I look forward to attending the conference tomorrow and Wednesday. (I found this after the fact so I have no idea what she is referencing and it really does not matter.)

In October of 2022 she started writing late one evening about herself. The notes are captured by scanning her writings. The scans are attached at the end of this book. I have transcribed the readable pages here. Some are almost unreadable as she crosses out and scribbles over those. (and complains about her handwriting.) I picked up her notes two days ago after she went to bed and it occurred to me that I could capture her thoughts simply by reading her notes.

She has told me over the past several months as her dementia worsens that she was sending and email to so and so. When I checked she had written a note much like the notes I have transcribed here. It suddenly occurred to me (AHA) that firstly I might not be able to speak to her forever and secondly, her actual words that she has written to herself might give me a glimmer of what concerns her most about this journey.

Her notes: (all written as bullets with a ➔ in front and a lot of line throughs)

- Begin to work on
- My experients (sic) in the Catholic
- I am
- My life as a Catholic throuough (sic) infancy
- I made my first commr when when I was 7yrs old
- I im grade school
- attended an all girls school (ICA)
- after graduation from Academy I began my studies at U C Evening College

- if I had pursued a degree at Marion College my path might has been easier at Marion College I would have pursued courses in education.
- However I was encouraged to attend other classes as I was not going to attend Marion College
- In hind sight several things in my high school education led me to my ~~next~~ January

I do not think this helps me understand her dementia better.

Christmas and Parkinson

Written in October of 2022

Cheryl has it in her head that Christmas is any minute now. The calendar fact that Halloween is next week does not dissuade her vision of the immediate future. Often when she makes comments almost daily now about cards, cookies, toys and generally shopping for the grand kiddos, I correct her and point out that we have about eight weeks to go before we need to worry.

We have only one grand child under the age of fifteen. My secret grand plan was to give every kid money and let them go find something that they covet. Zachary is only five so shopping for him takes us back to when the parents were that small. Good memories and fun times were had by all and I admit I like to shop for little people. (Maybe I should tell my soon to be fifty year old daughter that her mom is getting her a Raggedy Ann for Christmas. Be surprised and delighted. Is Raggedy Ann still around?)

So why are men so obstinate? Why am I stuck on correcting her delusion about the calendar time? I am not going to let her miss anything. She seems to not be disappointed when she indicates Christmas is next week and I say, no it is the week after or some such other baloney to satisfy her that the perceived need is not urgent. She wants to put up some Christmasy decorations. Why not? What is the harm if it satisfies her that all is in readiness?

Cookies
Two days ago like many days previous she wanted to make cookies for Christmas. Yesterday early in the day I put together the dough in preparation. It was our intention to make the cookies after we came home from dinner last evening. It did not happen as we became distracted with watching a couple PBS shows that are our favorites. I promised today after exercise class we would make cookies.

After a little lunch we got started on the cookies. In my maleness I sort of bossed her out of the way to start the process. Why I did that I am still discerning. Maybe in another life I will know why or not. She wanted to make the dough balls for the snicker doodles. I reluctantly backed off shifted into check-on-her mode.

Music
I once worked for a small company that had a six hour loop tape of Christmas music that played on the hold line of the office phone. One of the partners had read a book about how office workers liked to

hear and were more efficient with music playing. He piped the hold music into the overhead speakers. It was like working in an elevator that was stuck on the wrong floor. It was agony.

She said to me, “Get your music machine out and turn on Christmas music.” She means Alexa. I cringed when she told to do that. I think I grumped a little too and then I went to get the hockey puck I move around to listen to music. A Christmas song or two in among others is okay. WARM 98’s idea of solid Christmas music, old, new, good, bad, chipmunks, Benedictine monks, rock and roll, country-western, some group of nuns, Bing Crosby, etc. a few years ago lost me as a listener. That was not a big deal to them since I rarely listened to their station. Five weeks of Christmas music is agony to my ear. I feared the worst was going to happen – Christmas carols from Halloween to Christmas. There would be no “Monster Mash”. I said loudly, “Alexa, play Christmas music!”

Christmas music always makes Cheryl nostalgic. She remembers the olden days when she was a child. Nostalgia makes people tear up. Cheryl is no different. With her version of Parkinson, her emotions are on her sleeve. “I’m Dreaming of a White Christmas” started coming from Alexa. Bing was doing his usual great job. Cheryl was five when this movie became a favorite in the post war ‘50s. In the middle of scooping cookie dough into one inch balls she started to cry. There is nothing I can say to assuage her nostalgia and longing for her childhood. Those are most of the only clear memories that she has. A runny nose and drippy eyes are not useful for rolling cookie dough into balls for snicker-doodles so I eased her out of the way into a chair while I finished rolling the cookies.

I suppose we will do cards another day. Why are men so obstinate?

Carpe Diem.

Stories

I often write little stories in the third person as viewed from above. I apologize in advance for that. I am a victim of writing a Master thesis and it was emphasized as a style. I think of it as an out-of-body experience.

Untitled Story

When engineers look for a solution to some dilemma, they often spend a lot of time observing the problem.

Many thoughts can arise. Many questions seek answering. But ultimately the dilemma is slowly broken down to component problems and individual solutions to small problems are sought out. An engineering education teaches this process. An engineering education does not teach solutions for Parkinson’s disease and related issues. Those are discovered along the way.

"There's someone hanging upside down in the trees in back", she told me. There is a scrub tree growing in the weedy lot behind our condo. It has a crotch near the ground and branches into to smaller trunks as it grows toward the light. The bark is a light color almost khaki in color. To Cheryl it looks like a kid standing on their head. Perception is off a bit and her creative brain describes a different interpretation.

In that moment she pushed me into interpreting things and objects differently. Are painters able to do this spontaneously? Are story tellers able to imagine a different reality? Are engineers stuck with what they see and touch with little imaginative creation? It intrigues me, the imagination and story telling part. I have often thought that if I could get into her head I could help but maybe I would merely be steering her toward my reality and away from hers.

There are many changes that I notice in her behavior. She can easily ramp up an anxiety about indigestion. It is not apparent to me what specific foods cause distress. Milk products and foods high in milk and sugar seem to give her a hard time. Tomato sauces and beef with a high fat content also distress her stomach. The average time to relief is an hour to an hour and a half.
I have not discovered any silver lining in these episodes. It is challenging to distract her from focusing on how her stomach feels. After a severe episode she is typically awake much of the night. This happened last night.

In May of 2022 I purchased a new bed so that we would no longer awaken each other all night long. We slept for the first fifty-two years of our married life on a queen size mattress. We purchased a split king mattress in May, 2022. She no longer wakes me with her sometimes jiggling night moves. I no longer awaken her with my two or three trips to the bathroom with my old man's bladder. We both sleep better.

The Walk (how I remember it)

She put on her year old Nike walkers. It was one of those sunny spring days that says fresh and new is what we are up to today. I do not recall anything bad going on in our lives. It was the early part of this millennium. We both liked walking and hiking. It was our favorite activity for years. The years after our first complete empty nester experience are full of hikes in parks and simply walks around the neighborhood.

Where should we go? – c;

Let's go up Troy. I hate to go through the dip.- p;

Okay. -c;

There is a quick look around and search for keys and other kit.

What's the weather like? – c;

Warm. Probably no sweater. – p;

Are you sure? I thought it was supposed to rain. – c;

Nope. Sure. Look. – p;

He holds the door to the front porch open.

It does look nice out. – c;

Out the door and off on two miles or so.

Cortelyou (core-tell-you or cortil-you, your choice) avenue is named after John Cortelyou who either developed or owned that part of Pleasant Ridge. This neighborhood is located in north central Cincinnati, Ohio. On plat maps the area is referred to as the John Cortelyou subdivision. John and his wife Martha are buried in the Pleasant Ridge Presbyterian Cemetery on Montgomery. The pavement is narrow and parking is only permitted on the west side of the street. The part of the street that they live on if allowed to connect to it would make an acute angle to Ridge road. Troy avenue which meets Cortelyou just before it drops down a short incline towards Losantiville road makes the base of a right triangle with Ridge and Cortelyou.

Troy avenue meets Ridge road precisely where Ridge curves to the right to head south again after coming up the hill from the little valley that holds Amber creek. The short street meets the thoroughfare with an acute angle to the left and a right angle to the on the other side. There are mostly single family houses on the south side of the street and mostly multifamily buildings on the north side. It is a pleasant street. Narrow along its length but bright and sunny with few large trees along its length to obscure the view towards Ridge road.

Ridge road is poorly named because it never travels along a ridge in the earth but rather perpendicular to several. It would be more aptly named Over the Ridges Road but, no doubt, this name was rejected when the names were being given out or the makers of maps became tired of precision and in their gay manner shortened the name to Ridge rather than 'Over the Ridges' or 'On the Way to Ridge' or even 'Up to the Ridge and down Again' road.

As they walked they spoke of their surroundings and of people they knew. He came with her as he usually did on this day to get to know her better. They were empty nesters now. All three of their children were grown and moved away. He did not often want to simply walk around the neighborhood but she was okay with that she pushed him to get out of the chair and move. It is a nice day. Let's go.

They took the acute angle at the end of the street and walked north in front of the houses that were originally built, as the story goes, to show off the type of housing available to be built in nearby Norwood. No matter the back story these are beautiful old houses set far back from the west edge of the street. Some well kept. Some developing creeping overgrowth. An earlier majesty and grace left for some later owner to recover and let the homes bloom again.

At the top of the rise where the road dipped back down into the valley, they crossed into the neighborhood on the east side of Ridge. Through a small dip in the topography and up toward Grand Vista. Grand Vista climbs a hill to the left as they walked toward Montgomery road. This road is known as the Pike by the older generation.

At this point the conversation is interrupted to ask, up or not?

I think not -c.

Okay. – p.

Following Grand Vista to the cul de sac and back out will add over a mile to the walk. One can turn a mere walk into a trek in this fashion. They continue to Montgomery Pike.

Turning south on Montgomery they headed back into the business section of the old village of Pleasant Ridge just one of the ridges that over the ridges road went over in its meandering trail south toward the old village of Oakley. Near this turn anchoring one end of the business grouping is the Pleasant Ridge branch of the Hamilton County Public Library. They paused for a moment to allow a young mother to organize children, bicycles and a stroller as the family left the library with their booty.

It is a magnificent day for a walk around the neighborhood and they are enjoying themselves. The temperature is warm. The sky is the shade of pure blue that appears after a spring shower washes the air. The daffodils are near the end of their reign but stubbornly hanging onto their beauty as early tulips attempt to shoulder them out of view.

As they near Kincaid Rd. another key decision point he asks, Kincaid?

Yes, she replies.

They turn north on Kincaid on the west side of the street. During this entire walk p. has moved to her right or left to place himself between her and the street. In his own mind it is proper for the male to position himself between the female and the passing traffic. He is not certain where this ingrained behavior has come from. He merely knows that is what he needs to do. So, he has placed himself on her right side as they walk down the street.

…

As they walk he notices that occasionally she struggles to keep with him and this causes him to slow a little and look down at her feet. The walk is narrow and he thinks that perhaps he has hogged more of the width than he is entitled to. As he watches she is not lifting her left foot always. She is dragging it in a limping motion.

Being a man, he teases – are you having a stroke, dear?
She replies with – I don't know. My leg does not seem to work right.

They slowed more and he held her hand as they walked. She seemed to be struggling to maintain any sort of normal gait. When they got to Harvest they turned and headed back home.

…

I always remember Cheryl's initial struggles with Parkinson's this way. She remembers a different story. About this time she was a big deep water aerobics fan and participated in a class at the YMCA about three times a week. Later on we joined the Jewish Community Center and she did deep water aerobics there.

If you ask her she will describe going in circles in her water aerobics class when she wanted to go straight down the pool. She probably did that but what I remember most is this little walk we took one day many years ago.

A platitude:

> ***The best things in life are the people you love, the places you have seen, and the memories you have made along life's path. Carpe Diem.***

A Regular Day

There is no such thing as a regular day. Everyday is a completely new experience. Much of these notes I wrote and added to and gave to my daughter who planned to stay with her mom while I traveled to visit with my sister in June of 2021.

In my little blog I use a line from a Sheryl Crow song – *Every day is a winding road*. (I particularly like the bongos and the discordant guitar)

Generally this is how the day goes. Cheryl is awakened by me at 7AM when I bring her meds to her. (I no longer do this. I have come to realize that sleep, rest and exercise have equal value to Cheryl as she struggles with PD.) I encourage her to lay down a bit but she does not always comply. Often I know she did not sleep well and if she lays back down and falls asleep she is better during the day. My first disappointment comes when she refuses to even try to lay down after I am certain she did not sleep well.

She likes Life cereal, so often, when I am tired or simply not up to the task of making breakfast, breakfast is cereal with dried cherries and milk. On other days when I am hungry myself or simply feeling more “care-givey”, I will make pancakes, waffles or french toast. These are some of her favorites. If I have some fresh fruit or frozen berries, I will make and add a compote on top of the pastry. Breakfast it seems to me is her most important meal of the day. She may eat little for the rest of the day. She has orange juice with her meal. Usually six ounces but she might have two cups. She often finishes with some chocolate while she reads the puzzle page in the newspaper and works one or two.

After breakfast she will shower or just freshen up.

→ Day differences – between 10AM and approximately 4PM

→ 10AM meds and lay down. Up again and watch the View for a bit... If it's an exercise day, class is at noon, your mom will want to go at about 11:30AM. You will be early. Just go with it. If she is having a good day, go somewhere for lunch. Or on non-exercise days maybe go for a walk somewhere. She likes 4:30PM mass on Saturday.

I either cook something or take her somewhere to eat dinner about 5:30-ish. You may not be used to eating at this time during the evening. If your mom eats later that this she often has a hard time at night and does not sleep well.

There are frozen veggies in the freezer and frozen meats of various kinds. Two bowls have potatoes and onions in the pantry. There is rice, quinoa, dried pasta(s) and canned things. I went to the store yesterday and got yogurt, luncheon meat and bread.

Your mom likes English muffins and bagels. There are some of those in the fridge as is salad stuff.

Anna’s Expose

How it went with Mom (unabridged)

Wednesday:

Mom chose to stay behind as I gave dad a ride to the airport. As we were leaving she asked about logistics, “so you are going to drop him off and then go get your kids?” I clarified I was coming right back. No kids. I received a text from Natalie on my return trip from the airport informing me mom was still confused about whether I was coming back and when. She went to Jane’s to wait until I got back. Jane mentioned emotions were closer to the surface than she had seen before, but she was fine. Had a nice conversation for a while with Jane and left @4 for obvious reasons. She then laid down.

Eventually there was a lot of confusion/activity about what each of the keys do.

Then there was the "what would you like for dinner conversation." During which she told me she would make pancakes or waffles for breakfast. Mom got really excited about my frozen blueberries that I brought for my smoothies. Didn't really know what she wanted for dinner. I spied pasta, sauce and salad. Easy enough. She didn't really want salad but she ate it all. Then she found ice cream in the freezer for dessert.

She kept herself pretty busy trying to find a picture or a name. In the meantime she had lots to say/share on a variety of topics. Somewhere in there she played voicemail messages Dad left her before his first fight. She asked me where he went and remembered as soon as she asked.

As it approached 10:00 she decided she needed to go to bed. I reminded her of her last round of pills for the day. She then had a slight concern about who was going to bring her her medicine in the morning. Talking about the guy who usually brings them. I just told her I would bring them. She seemed ok with that and wandered off to get ready for bed.

Fun personal note: I learned mom is why I do not like a toilet left open after use.

Thursday:

I turned off the annoying bedroom alarm and delivered her medicine. She then informed me she was laying back down for a bit. By 7:40 she was up looking for breakfast. So I quickly learned about the waffle iron and recipe on the Krusteaz bag. Cleaned her plate. Then she wanted tea. I followed Dad's instructions. Dad eventually called. We all chatted. Then around 9:15 she decided to exercise. She found the things she needed and got busy.

Max and a friend were going to a reds game. The girls rode along and came here. Lauren gave mom a ride to her exercise class while I finished the drive to the stadium and dropped the boys off. Lauren and Audrey exercised with mom. Virginia and I made it to the fitness center before it started but sat near the door until they were finished. Then all of us girls went to Frisch's for lunch.

Then home…

"What should we do about dinner?" What would you like mom? We settled on sandwiches. What would you like on your sandwich mom? "We could fry bologna and maybe add some cheese." "We could toast our bread." What would you like with your sandwich? "We have pork and beans. I'll fix some up." Fried bologna and American on toast with a side of pork and beans (ketchup and brown sugar added of course) for dinner!

There was talk about wanting to visit/call Robby Rose. I found the very start of the movie Wonder. We started to watch it then dad called. Mom not understanding it was on tv wanted me to stop it so she didn't miss anything. I quickly discovered we had started at the beginning which meant when I hit record we would have all saved on the DVR. She went to bed when there were 20 minutes left.

Friday:

Gave mom her medicine at 7 am and she was up! So I packed the couch back together. Made coffee. She ate breakfast by 8:00. I made use of the trails on the old golf course for half an hour. Came back and she had showered. I made use of the 8 lb weights and then showered, while she watched her favorite sitcom and then the View.

Decided to go out for lunch. After discussing options, Slatts is where we went. Good food. Then wandered home by way of a gas station (filled Dad's tank☺). Mavis brought Zach over for a visit and mom got out the Thomas set to show Zach. They left around 4:00 for Zach's nap.

Mom laid down for about half an hour. About 45 minutes after taking her 5:00 meds there was a round of dry heaves. Did eventually produce a little something. Not sure if something should have been done differently to prevent them. She said not. I poured some coke and crossed my fingers that her stomach settled. She could not find relief. After almost two hours of dry heaves (with occasional stuff), she and I decided I should call the doctor's office for some advice. I was actually patched through to Dr Duker himself. He listened and was concerned about getting the nausea medicine in an IV as well as electrolytes. He advised that I get her to the ER so she could be checked out.

I called Scott and asked for his help. He came right over and helped me get mom to the hospital to figure it out. Shortly after being given a disintegrating pill she was ready to go home and frustrated it was taking so long. Pill was effective. Eventually they let us know that they checked everything and she looked good. Sent us home with a new prescription. Took her 10 pm meds at 12:45am. Got her in bed. Scott hung around a bit and I got to sleep by 2:00.

Saturday:

Set all my alarms to make sure we got the 7 am meds in. She was up. I was not ready to be up. Found her Bob Heart ♥ Abishola show and put it on. Then made her waffles. There was a light headed moment. She laid down. It passed. She was back for waffles.

I asked Jane to come sit with mom while I got her prescription filled. After I returned and Jane left, I was making her bed when she said:

"I have never had the opportunity to stay on first floor living quarters before. This is pretty nice. They arranged it like my place. They even made copies of my pictures and hung them on the walls. The woman that runs this place does a nice job."

She laid down for short naps. Last one she popped out of her room at 3:09 asking where her mom was. After I politely corrected her, she then wondered if anyone wanted to go with her to 4:30 mass. I said I'd be happy to take her, just needed to freshen up. Off she went to shower.

Side note per Sr Karen:

Karen Schall picking mom up and taking her to lunch @ Mios at noon Wednesday.

Also Mrs. Potter said next time she goes to 4:30 they are calling to confirm you are going in order to plan for dinner after mass. They are headed to Florida this week, so it will be a couple weeks.

Got Mavis and kids to meet us at Mio's. Mom was excited and told me how to get there. When we were finished she began recommending parks to go to. "We could go to Bechtold park…" Mavis was in. Walked around while Zach ran around and then she fizzled on the nearest bench. During all the walking and driving home she had lots to say about extended cousins and all the fun she had young and how sad she is because I didn't have that kind of relationship with extended family. Out came the spreadsheet and all affiliated piles of paper clipped family tree documents for her to reminisce.

Lunch with Sr Karen made it on the calendar.

Sunday:

She was up at 5:30 to use the restroom, and came out to the living room to find a place to lay down because someone had taken her place in bed. I convinced her all was well and she should go lay back down for a while. At about 6:45 she was up to use this bathroom, because she "didn't want to step around the little kids on the floor up there."

She had her usual juice, cereal, and tea. She seemed to have some energy about her. I threw out the idea of a walk, and she was off to change her clothes. We went to the park she likes. She started out at quite a pace. Then half way around she ran out of gas, but we made it to the car just in time for 10:00 meds. When we got home she was tired and laid down while I stepped across the road and walked the path.

When I returned at 11:00 she mentioned being hungry, so I made her a fried bologna sandwich. She worked her puzzles. Took her 1:00 meds. By 1:30 she was overwhelmed by nausea. I gave her a disintegrating Zofran. It took most of an hour, but she did return to a much better state. I have decided to try a steady Zofran dose (every 8 hours). So I plan to give her another at bedtime and new stuff, not old stuff for 7:00am tomorrow.

She had Mio's leftovers for dinner at 5-ish. Then got busy on her computer. I brought a knitting project along with me. I was looking for a sewing needle and thought mom might have one. She did not, but my inquiry brought about a lot of unboxing and unpacking the closet. The first trip through, I said, "It's ok, I will find one tomorrow. Don't worry about it." I sat down to knit a little and she came out a few minutes later getting a chair. She had run out of places to sit. I went to investigate and she had half emptied the closet and was working through boxes we had searched earlier. I convinced her to let me put it all back and leave it. She really wants to shred old bank statements and thinks the condo needs to be cleaned thoroughly and repainted.

7:00 she took meds and was in her recliner with all the things by 7:15. Took about 30 minutes to get through. She then headed back to her computer. While checking new phone messages, she landed on old messages. She thought Kirkland's office was confirming surgery for tomorrow. She was worried there was something she missed and did not want to get charged for a no show tomorrow. I tried to point out it was an old message and there was no reason to call anyone on a Sunday night. She just wanted to leave a voicemail explaining their mistake. Had Scott call her to change the subject and see if that distracted her. Then she was trying to call her mom on her mouse. I gave her a hug, while I thought through my next approach. I eventually found Michael Buble and the puzzle were a way out of a ridiculous confusion cycle. We worked it for about an hour. Then she fizzled out by about 9:45. She took all meds including a Zofran.

I did learn that donuts are usually on the menu for Sunday. I learned it too late, after she had her late day spell. Might find donuts tomorrow…

Monday:

I slept all the way until the crazy annoying alarm. Had to work a little to wake Mom at 7:00 for her medicine. Gave her the new Zofran instead of yellow equivalent along with the rest of the 7:00 pile. She decided she was up. Had her cereal. Tea. The watched some of the Today Show. She showered was upbeat, herself. After 10:00 meds, she chose to lay down while I ran to JoAnns for a couple sewing items I needed. When I got back we went to the Bridge House for lunch (BLT not a double decker).

I was determined to make serious progress on a sweater project. Mom was determined to write to Robby Rose, work on an email about party at Barb's, and organize for Clementines and PD support group. She was working and playing Michael Buble. He's growing on me. It was a good afternoon. At 5:00 I suggested we think about dinner. Maybe Strong's since she was talking about it earlier. I learned after we approached the parking lot that they are closed Monday. Oops! Arby's was on her mind next, so we went through the drive through and brought it home.

After we finished eating she headed back to her office and organizing stuff. I went back to my project, with an eye on what she was up to and how I could redirect her sooner if needed. I asked her what shows were on Mondays. She was happy to report her Abishola show was on at 8:30. Kept that in mind for later. She was in a printing state of mind again. Apparently she had made a change to the spreadsheets we printed the other day. I helped her print one. Then she wanted 10 copies. Then a little later I thought she was breaking the printer. First I removed the card stock and photo paper from the printer. Then I figured out how to make copies of the support group sign in sheet. The ink was running out, so I cut her off. "No more copies. You show is going to start soon."

She was in her chair before the start of the show. She really likes that show. Somewhere during a commercial break she started talking to me in a way I knew she thought I was someone else. It wasn't obvious to me who. I just wanted to play the part. I always answered her honestly but did not correct her. I figured her head would work it out. She quickly faded around 9:45. Had a tough time changing for bed. First time I felt the need to help with all aspects of getting dressed. She was pooped.

Today there were no overwhelming nauseous moments.

I gave her new Zofran 7 am, 1 pm, and 10 pm. Not exactly 8 hour increments, but only 3 doses in 24 hours within established schedule.

---++---++---

I really appreciated her notes about Mom. I gave me a bit of insight into how Cheryl dealt with me not being there.

The Day the Birthday Cards Stopped

Anna was looking for ideas about what to get her mom for her birthday in May of 2022. I suggested a box of blank cards to send for any reason. Cheryl has always kept greeting cards that are sent through the mail for fund raising purposes from various religious and chronic illness organizations. Some would be sent to her mom when Elaine was still alive. Some of these are still in residence in Cheryl's office.

There is a small green box shaped like an old country mailbox near the phone in which these cards used to reside. They are no longer there but are spread here and there amongst other paper and chaff in her office. I had hoped that Anna's present would take up residence in the mail box topped box but that did not happen.

In mid-April of 2022, I suggested that she should make a list of the May birthdays and we would make a trip to the store to get some cards to send. The idea of making a list is hers. She readily agrees with this idea but as her Parkinson took hold of her cognitive centers she is unable to do this.

A few months back her engineer husband suggested that rather than a list she should write each name on a post-it note and as she selected cards in the store, she could put the post-it note inside and she would know who the card was for. Later when she wrote the card and addressed the envelope she could note what date she wanted to mail it and stick it to the front when she sealed the envelope. That solution met resistance because of the NIH factor. (not invented here) But over time she adapted it to her way and used it for awhile.

In April I helped her make a stack of post-it notes with names and we went to the store for cards. Few of those cards were ever mailed to anyone.

In May I waited to see if there would be a panic mailing of cards. May came and went.

Our daughter-in-law Mavis's birthday is the 1st of May. Hers was the only May birthday card sent. How do I know? In a previous month there was panic as Cheryl realized she had forgotten where she had put the stamps. I now keep track of the stamps. I often have written about her punding. Sometimes she will pund stuff into obscure places. We all do this – not punding – but set things down in obscure places. With PD it is merely harder to find out where it was parked. The stamps turned back up a week or so later after I had bought a new roll.

Cheryl's birthday is in May also and her brothers and sisters often gather for a "sibs" dinner to celebrate such an event. These pictures are from that gathering at Gabbey's cafe.

The birthday cards acknowledgment of the family birthdays seems to have been forgotten. It is probably another nuance to he loss of sense of time, calendar, day, week. Our son Scott's birthday is the 6th of June. We were at our daughter Anna's house on his birthday. Anna asked her mom whose birthday was today. Cheryl looked at her with a confused look.

I felt sad about several things. I have been writing significant events on a white board that I put on the table each morning so that Cheryl knows what is happening this day. I have not been writing down birthdays. She forgot Scott's birthday. Of the few cards that I think she should send we forgot to send one to our son. A few other sad thoughts drifted through my head. But most of all I realized that she had lost the birthday card duty. She had forgotten it. This is a long time thing that she did for our family and her mother while Elaine was alive. This is a longtime activity for her. Her short term memory has been off or fading for sometime. I had gotten used to the fact that it is necessary for me to remind her of events constantly. (It is annoying but over time one gets used to it.)

Christmas, birthday, invitation, funeral cards are all gone. An actual paper card with a USPS stamp is how Cheryl learned to acknowledge things. She never adopted Facebook or any other social media platform for those.

Parkinson is a series of small setbacks. Sometimes it is so gradual it merely seems like life going by.

This topic about the birthday cards occurred to me in early May of 2022 when no panic mailing of birthday cards or frantic searching of the black book (more later) or of the old address books that we had in our old house or her mom's address book. It was a sudden occurrence in her behavior.

Could I be watching apathy creep out from behind the curtain? I will have to be alert to this behavior. So far Cheryl does not seem apathetic. She does have a fading memory.

Carpe Diem.

We Hiked a Lot

It was a favorite pastime. Once we went to Greenbow Lake State Park in Kentucky. It was March. Early in our empty nester experience we could simply pack a bag and leave for a couple days. It takes more planning these days.

That March about twenty years ago the weather was predicted to be swell. We had no plans for anything so we left town to go hiking in the woods.

It seems like a long time ago now.

When we left on one of these spontaneous hiking excursions the first thing Cheryl would do is collect all the park maps with trails. This time she selected an eight mile loop around the woods near the lake. I can still hear her say, it's only eight miles. I probably said okay without any follow up questions, such as, how far to the trail head?

Two miles was that answer.

We had breakfast that morning in the park Lodge. As an aside, Kentucky has always done a great job with their state parks. My parents took our family when we were children and we took our kiddos when they were children. Cheryl and I stayed at one on our frugal honeymoon. We started revisiting that particular park after our silver wedding anniversary and enjoyed our time in that part of south central Kentucky for many years after.

With her latest nuance of Parkinson in our life we no longer visit these hilly hiking arenas. We have become flat-earthers in so far as hiking is concerned.

After breakfast we took off at a rapid clip towards the trail head. In March in eastern Kentucky the landscape is still grays and muted browns but here and there early spring bloomers appear. I am not a skilled horticulturist but crocus seem to like hillsides and cool weather. On this day however the weather was perfect for hiking. A warm sunny day in early Spring lifts one's spirits and makes me hunger for summer. I was hiking with the love of my life and we were enjoying the day.

About two thirds of the way around our loop we discovered a fire ring with some log benches and a nice view of the lake, so we rested for a bit and enjoyed the view of the lake and listened to the squirrels hunting up their caches of sustenance that had been stored the previous Autumn.

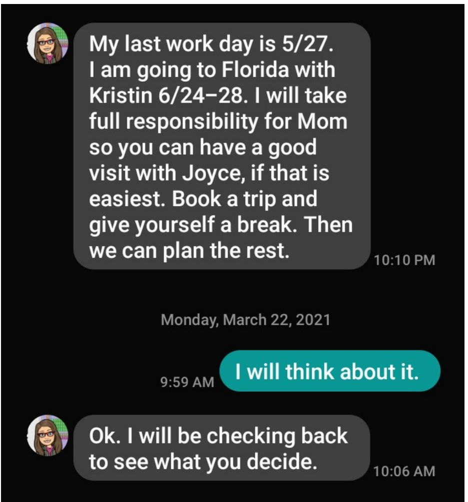
A few minutes later the squirrels and the other small wildlife scattered as a group of what turned out to be young scouts smashed their way down the trail from the opposite direction with something much less than a stealthy hike to their fire circle. We exchanged greetings and moved on with the rest of our hike. As we left we could here the scouts chitting and chatting between themselves. How did those old people get way out here? Are they lost do you think?

Cheryl and I giggled and talked about it all the way back to the lodge for a little lunch. Lunch was very good that day. The Lodge food operation had a buffet set up with soups and salad and my favorite, corn bread. I had about three bowls of bean soup. It has heavenly and the corn bread was shaped into pancakes, not the johnny cake that we city folks are used to eating.

It was a five hour trip as I recall. The bean soup was much appreciated. The nap afterwards was well deserved.

Emotional Tug of War

My daughter sent me this text last night. I love her and her mother dearly.



My last work day is 5/27. I am going to Florida with Kristin 6/24–28. I will take full responsibility for Mom so you can have a good visit with Joyce, if that is easiest. Book a trip and give yourself a break. Then we can plan the rest. 10:10 PM

Monday, March 22, 2021

9:59 AM I will think about it.

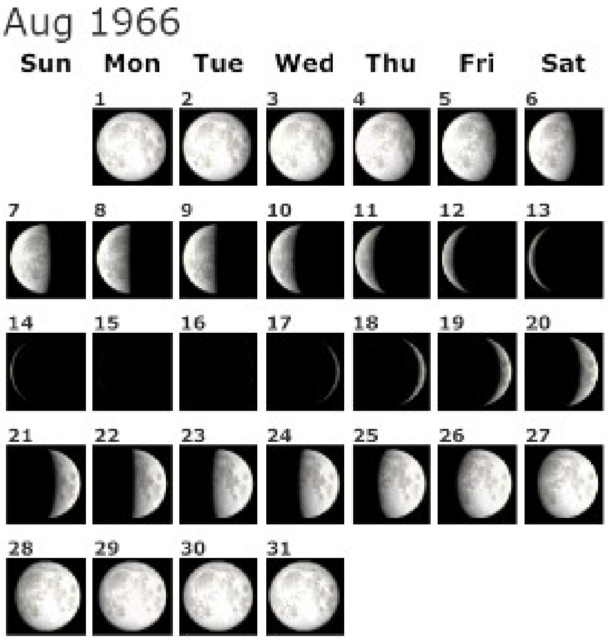
Ok. I will be checking back to see what you decide. 10:06 AM

She has determined that Dad needs a break from the covid, a break from the Parkinson's, a break from the constant care giving and checking and keeping track of stuff.

Sometimes children, good friends or simply others can perceive what we cannot. Solipsistic Dad is unable to detect the forest when the trees are in full view. This is March, so Joyce and I will be able to plan our visit.

As it turns out our nephew is getting married in June. That is so perfect! I have not seen Jeffrey in person for a few years. The wedding was supposed to be last year the covid year and it did not happen. All of California was closed last year for a while. This is developing into a sweet summer.

Looking back on this trip from the distance of about a year and a half, it was a great time. With the pandemic in full swing the service was not the best but I had treated myself to seats in the front of the plane and that part was great. By the time I went we had the first pair of covid vaccine inoculations from Pfizer, so my only worry was that some virus denier would breath my air.



We Met on a Blue Moon in August

It's amazing actually. We met on a blue moon. Look at the chart of the moon's phases here. It came from stardate.org. I looked for the information after Cheryl and I took a walk in the park. The park was Winton Woods. It was the place where we first met.

I first started these notes eleven years ago. We had taken a winter time walk on one of those magical days in January when the sun is shining brightly and the temperature has climbed above forty in the Ohio valley. An absolutely wonderful day to walk with my wife of forty-two years.

Life was still grand. Her Parkinson's disease did not consume much effort but I have digressed from the story.

Her memory is one of a big full moon. I don't remember that. My mind was on other things that night. Finding a girl was not one of them. Being cool and one of the guys was. Oh well, a busy life and many years gets in the way of memory.

Her memory is better. We did meet on the 30th of August of that year. The end of the summer between our junior and senior years in high school was drawing to a close. Some of my friends had arranged an end of the summer picnic in Winton Woods Park. Grill some hot dogs, drink some cokes, laugh it up, kiss the girls – It was not intended to be a big deal. At that part of my life, having girls around still scared the crap out of me. I was still grappling with all those emotions and hormones and pheromones stirred into a blurry soup of teenage-hood and manhood. So, I went with reservations. I had ticked off Mom a week or so earlier and she had grounded me. And girls still scared me. Also, I did not know any of these girls. Many of them went to Our Lady of Angels High School an all girls catholic school in St. Bernard. Where is St. Bernard?

So, ten or so years ago – regardless of any of these thoughts (remembrances) Cheryl and I figured that we met on a blue moon. It is now 2010. We are still together. Proving what? Perhaps it is important for the first night to be special. It probably is for all but they don't notice at the time. I know I did not. Fortunately Cheryl did.

I wrote that about eleven years ago. This story is chopped up a bit but Cheryl's memory of this even through the Parkinson's fog is very clear. It got me to thinking; perhaps I should put down my thoughts before I don't have any more of them.

We were married four years later – exactly minus a day.

As Time Moves On

I first posted these thoughts on July 16 in a bit of melancholy. Melancholy and grief for abilities lost come to me when Cheryl is feeling tired and down from lack of sleep and simply too much activity. This little moment of nostalgia has passed for me but her confusion about life and other activities continues.

Yesterday evening she told me that the notes that Tari, our sister-in-law, put in the cards are too confusing so I am going to bed. I chuckled to myself.

Cheryl has taken over her mom's task of sending birthday cards out to the kids and grand-kids. Last month I started to help with the cards because Cheryl had struggled with who she had sent cards to previously. Some got two cards.

I conjured up a system in which I put everyone on a separate Postie note. As we picked out each card I put the postie inside each card. When she addressed them all she read the note and wrote the envelopes out. This month she thinks Tari wrote out the postie notes.

A few minutes ago I went in to check to see how she was doing. She told me that Tari picked out some really cute birthday cards this time around. (Tari was not with us shopping for cards yesterday but that is not important.) She is working on the August birthday cards. She had just put on her favorite Rod Stewart CD on the player in her little office. This song came on. It happens to be one of my favorites. This disease of Parkinson is slowly taking her from me and I long for the old days.

What good are words I say to you?
They can't convey to you what's in my heart
If you could hear instead
The things I've left unsaid
Time after time
I tell myself that I'm
So lucky to be loving you
So lucky to be
The one you run to see
In the evening, when the day is through
I only know what I know
The passing years will show
You've kept my love so young, so new
And time after time
You'll hear me say that I'm
So lucky to be loving you
I only know what I know
The passing years will show
You've kept my love so young, so new
And time after time
You'll hear me say that I'm
So lucky to be loving you
Lucky to be loving you

An old standard by Rod Stewart

It is a lament of times passed and an optimism for the future. I often struggle with that last part when this disease of Parkinson appears in the middle of the night or I am researching incontinence products on various websites. On melancholy days I think about the preParkinson times. It helps to not look back with longing for those experiences. Time only moves forward. I am grateful to have had those experiences with her. I am grateful for the times we have yet to experience.

Do I wish she did not have Parkinson's disease? You betcha.. Cyndi Lauper has a song that might be more familiar with a similar sentiment. Once in a while I get very nostalgic for our previous life. I let it roll over me in waves. It is helpful.

Tonight's menu is Salisbury steak, rice, green beans and corn. I am baking a small cinnamon crumble cake for dessert. These are some

of her favorite foods. I am following the Dinner for Two cookbook by Betty Crocker which is her favorite cookbook. She will compare her version before our kiddos came along to my version this evening.

Hopefully the hallucinatory little girls that often populate our home in the evening will not appear and we can rest later.

She is looking for earrings after she awoke from her nap.

It seems that as time goes on the hallucinations are more common. It seems as time goes on she is stiffer at night and needs help to get to the toilet. It seems as time moves on she is more confused about her surroundings. It seems as time moves on she has difficulty sleeping at night. It seems that as time moves on her short term memory has completely failed. It seems as time moves on she has little concept of time – day and night can seem the same to her. It seems as time moves on the calendar holds little meaning even though she writes appointments and meetings on it. It is annoying to her caregiver.

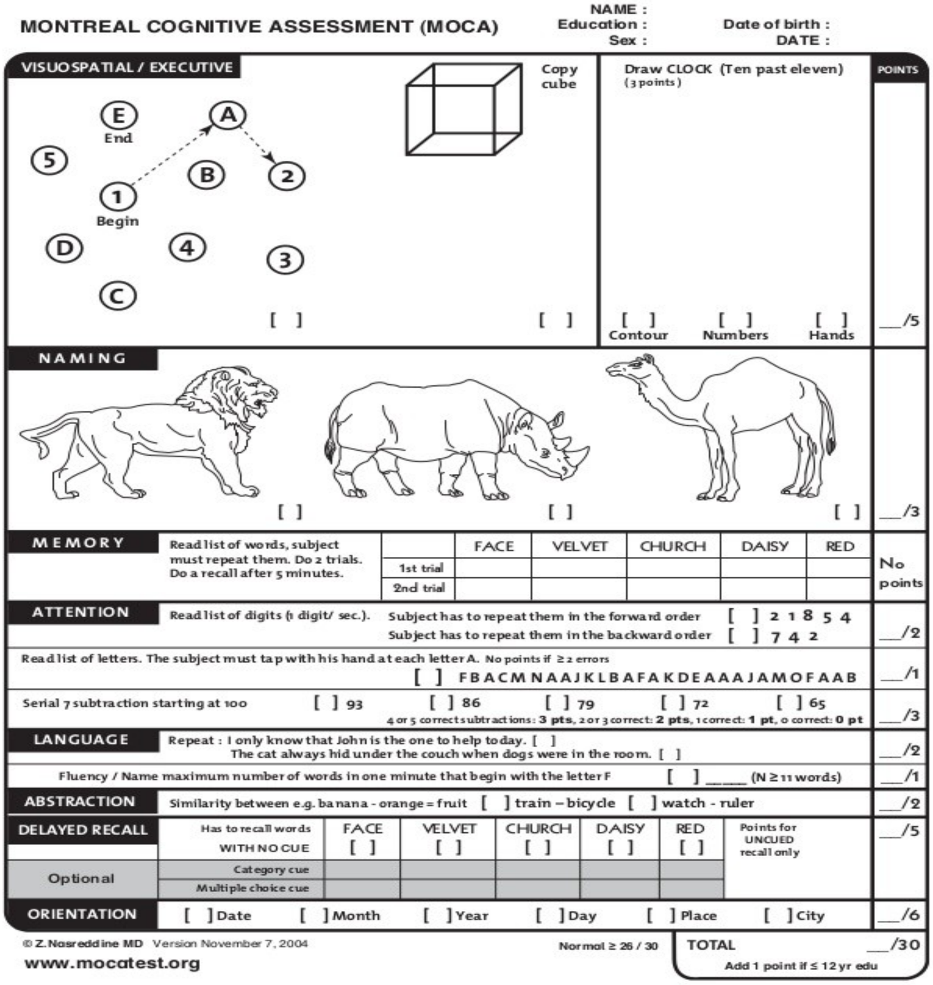
Sometimes Life is Funny – Just Laugh at It

It is important to just laugh at the situation and move on. This is a story about poop, Parkinson's disease and mental confusion so if that happens to disgust you gentle reader, read no further.

A couple years ago when when my wife of fifty plus years realized that her disease was worsening became very interested in doing anything that was possible to help with finding a cure or at least helping with research that could mitigate others' suffering. Rather than give in and give up, she started her own support group in our church to provide a forum for information exchange. She volunteered to be a part of a research program conducted by her team of doctors at UC Health. She wants me to figure out how to send her brain to UC for research and analysis when she dies. She has thrown her confused self headlong into the Sunflower Rev It Up for Parkinson's annual fund raiser for UC research into causes and cures for Parkinson's disease.

Her attitude generally is – prayer is a wonderful thing but God helps those who help themselves. Get out of your chair and do something! I love her.

Poop is part of this story. The research study is mental, physical and medical. Each session involves the trump mental agility test otherwise known as the MoCA. (The Montreal Cognitive Assessment (MoCA) — a widely used screening assessment for detecting cognitive impairment. It was created in 1996 by Ziad Nasreddine in Montreal, Quebec. It was validated in the setting of mild cognitive impairment, and has subsequently been adopted in numerous other settings clinically.) In addition to the MoCA there is a long series of questions and the clinician interviews her about her current symptoms. Everything is recorded in a database.



MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :
Education : Date of birth :
Sex : DATE :

							POINTS
VISUOSPATIAL / EXECUTIVE [ ]	Copy cube [ ]	Draw CLOCK (Ten past eleven) (3 points) [ ] Contour [ ] Numbers [ ] Hands					___/5
NAMING [ ] [ ] [ ]							___/3
MEMORY	Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.		FACE	VELVET	CHURCH	DAISY	RED	No points
		1st trial						
		2nd trial						

ATTENTION Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4 Subject has to repeat them in the backward order [ ] 7 4 2	___/2
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B	___/1
Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**	___/3
LANGUAGE Repeat : I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]	___/2
Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)	___/1
ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler	___/2

		FACE	VELVET	CHURCH	DAISY	RED		
DELAYED RECALL	Has to recall words WITH NO CUE	[ ]	[ ]	[ ]	[ ]	[ ]	Points for UNCUED recall only	___/5
Optional	Category cue							
	Multiple choice cue							
ORIENTATION	[ ] Date	[ ] Month	[ ] Year	[ ] Day	[ ] Place	[ ] City		___/6

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www.mocatest.org

Normal ≥ 26 / 30 **TOTAL** ___/30
Add 1 point if ≤ 12 yr edu

Here is an image of the test: (I have taken this test also. I suspect that it is given to most anyone with gray hair.) Physically motion sensors are strapped to her wrists, feet, chest and hips. The research clinician has her do several specific motions. The time of her last dose of medication is recorded. Walks up and down a long hallway and a computer captures her motions. She is given a smartphone with a special App to record her motions for twenty-four hours. Cynthia, the clinician, instructs me on how to start the special sleep mode app for recording her while sleeping.

Medically; blood, urine and fecal samples are collected. There is a growing body of research that connects PD to activity in the gut. During the walk around testing Cheryl needed to use the ladies room, so the urine sample was collected at that time. Cheryl finished up with the interviewing and testing and walking. The clinician asked if we (she directed this at me) were able to do the fecal sample. I replied, "Sure" with as much enthusiasm as I could muster. Cheryl had her smartphone collecting data in her pocket and her smartwatch on her wrist sending the data. We headed downstairs to draw blood. After the blood was drawn we headed home with our bag of stuff that we would return in the next couple days after the poop presented itself.

About poop; constipation is, in addition to a problem with those who do not eat enough plant material and soluble fiber, a common dilemma with Parkinson's patients. Once a PD sufferer has a completely backed up system other problems arise. The most common is nausea for severe constipation. Simply being uninterested in food and eating very little is also common. Many cannot discuss poop without giggling. Go ahead, we do.

A week previous to this, I had traveled to California to visit with my sister and see my nephew get wedded to his girl friend and fiance of four years. During this trip my daughter stayed with her mom and on the second night Cheryl had a severe bought of nausea that caused my daughter and son to take Cheryl to the hospital to find a solution. Zofran did the trick and in the meantime the hospital did a CT scan of Cheryl's abdomen. The report itself is a marvel of information that boils down to — my spouse was full of crap. Much more crap than should have been there. (Stop laughing.)

Sadly the hospital did not give this information to either my wife or daughter. No recommendation for a laxative was given. Cheryl was given a script for 4mg of Zofran ODT. Her neurologist has a word he uses for situations like this – odd. She had a prescription for 8mg of Zofran already. It was not for the oral dissolving tablet.

Later after reading articles about PD and meds, I discovered a study done specifically with this drug and tie oral dissolving tablet. There is evidence to support the fact that this version is more useful to PD patients. Whether it is what is added to make it dissolve in the mouth or simply the fact that PD patients need not swallow it was not clear to me. I asked that Cheryl's prescription be changed and the doctor readily agreed.

I convinced Cheryl that she should start with a laxative the day following my return and after I had read all the information from the late night hospital trip. After the second day the laxative was working. Never in my wildest dream as a new husband did I ever think I would be concerned with my wife's poop fifty years later.

I wanted to go ride my bike the day following the research study trip. I had been hanging out waiting for the laxative to work and collect the poop for the betterment of mankind when I asked my wife if she thought that was going to happen. She said, "No. Probably not for a while." I had explained that if poop came just don't flush I will get to it when I get home.

I decided to go ride my my bike for a little exercise. So I did and poop came.

Confusion and excitement ensued when I was not there to consult about what to do with the poop. I think Cheryl became confused and remembered that I had said, "Don't flush." Sometimes, however, she sees small children and she was worried that they would steal the poop or flush the poop or just simply mess with it somehow. She did not call me but she did call our daughter who quickly assessed that Cheryl was confused. Cheryl wondered if she should call the hospital to find out what needed to be done with the poop. Our daughter assured her mother that it would be okay. She should close the toilet lid and put something on top so that the kids could not get in and the poop could not get out.

When Cheryl seemed okay with that Anna called me and told me all about the poop emergency. We laughed a bit over the phone about the situation and she hung up so that I could call Cheryl. That took two or three tries before the cellphone connected to my car and we chatted about poop for a while. Ten minutes later I collected the fecal sample in the kit. Cheryl stood nearby because she wanted to know what to do with it next time. It being the poop.

We had a good laugh afterward. I have laughed with my daughter about it also. In the end all was well. The poop was collected and sampled not messed with or stolen. Mankind will be saved. Crisis averted.

A Monotonous Schedule

Regular routine seems helpful to sleep patterns. As we get older and further down the Parkinson road there is less spontaneity. The typical day described previously to my daughter Anna provides some stability and routine that we can hang other things onto. It also provides a tedium that cannot easily described.

However, there is a big wonderful world out there and it is important to get out and do things in it. We discovered this in the midst of the Covid-19 pandemic when, suddenly, our little diners and bars were closed. Suddenly we couldn't go out for no other reason than to get a sandwich and watch the world for a bit. We did very few social activities as it was simply because it was "too hard". During the pandemic they were all stopped.

Purses, Zippers, Pockets

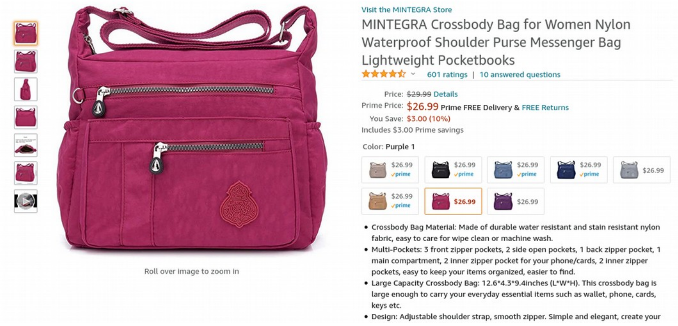
Cheryl really did not use a purse much. She had one she used when the children were small but with small children there is a lot of extra baggage and equipment so overtime she consolidated everything. So it is my recollection that she did not carry a purse but I am thinking that is probably incorrect.

As her neurological condition degenerated I encouraged her to carry a purse. I helped her find a purse that had a long strap that she could drape over her shoulder and would not require her to keep a hold of it with one hand. She needed more and more to have hands free to keep her balance and grab me or the door frame or the car or the back of a chair or the back of a bench or a stair rail or something.

The first bag I helped her find was a smallish brown leather purse that was perhaps 10 inches by 8 inches and a depth of 4 inches. She carried little with her. In my maleness it seemed adequately sized for the couple of things that had to go along. Glasses case, small wallet, keys, a pen or two, a small package of tissues, this purse had room aplenty for all of these. We left Target with our prize one evening after eating in Frisch's restaurant across the road from Target.

Two things happened over a period of weeks. The strap, although it seemed adequate at the time became inadequate. The capacity mysteriously reduced in much the same fashion as a cotton T-shirt that had resided too often in a hot water bath to be cleansed.

Back at our favorite Target store we found a somewhat larger green cloth purse with a different style of strap which I thought could be made much longer. Alas I was foiled by the fact that the straps did not get longer as it first appeared. The straps converted the purse to a mini back pack. Unsure of what to do about that situation or whether it might prove useful for Cheryl, we gave it to one of our granddaughters who happened to be visiting a few days later.



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- Design: Adjustable shoulder strap, smooth zipper. Simple and elegant, create your

The selection at Target seemed to be shrinking. I started to search Amazon for a suitable new carryall to replace the rapidly shrinking brown artificial leather messenger bag. One night the pinkish purple purse appeared in my Amazon search window. It is available in other colors and made of a canvas material. Most importantly Cheryl likes it.

It has other features that are not readily apparent. It has a total of five zippered compartments (six if you count the one inside another). These provide the entertaining feature of hiding most anything that Cheryl puts in there. Additionally there are several internal zippers that provide further confusion for any parkie. It is, even without these extra attractive accouterments, a fine messenger bag with plenty compartments to organize one's stuff whatever that stuff may be.

This purse can be a distraction and an entertainment. Cheryl often zips and unzips one or two or three zippers as soon as she spies this purse benignly resting on the edge of the table as it is shown above. It is a delicate dance between her and the bag. Men cannot understand the attraction to the zippered compartments.

Parkinsonism must provide a bit of obsessive-compulsive (punding) attraction to the zip itself. Much like a fidget spinner the zipping happens but somewhere in her thought process she puts stuff in, maybe takes it out, maybe not, maybe moves it so that it is in a better situation.

She seems in no hurry to disparage this bag and its features. Sometime she will complain that it has too much in it. That is good information.

Occasionally to Her I am a Different Person

> *"Not everything that is faced can be changed, but nothing can be changed until it is faced."*
>
> *James Baldwin*

I do not know much about James Baldwin. He was a black man and an author. He wrote "Go Tell It on the Mountain" and other things. He died a while ago. This quote which I tripped over this morning reading through other articles not from mainstream media as my sister-in-law likes to say, spoke to me. Lately, Cheryl has been struggling with seeing extra people in our home and upon occasion, though not wondering who I am, seeing me and sometimes not seeing me.

Yesterday evening she asked me if I had talked to Paul about something. I do not remember what the something was. It was not important . I quickly realized that she thought I was not me. I replied with I am Paul.

These moments seem to come early in the morning or late in the evening. It is dark. The lights are on here and there.

She talks about dad doing this and dad doing that. The first time she started telling me about dad was when I changed the dimmer switch on the light fixtures in our master bath. I had added a newer dimmer control with a toggle. I had thought it to be more convenient for operation in the night. It is and she approved of its installation. She told me so that night by saying – did you see the new light switch dad put in? It works great.

I did not ask who she thought I was. I merely acknowledged that it was a good thing that he put it in the bathroom.

That guy who brings the pills… is a common early morning remark lead in to some comment I said when I got out of bed to turn off the alarm and retrieve her first dose of medications for the day. There are many of these; That guy who brings the pills in the morning, he said we were going to the store today. (for example)

Extra people appear to her in our home. Not religious apparitions but little girls and sometimes their guardian an older woman will appear with them. A few days ago when I returned the bowl that had contained her pills and the water glass to the kitchen, she asked me what that woman wanted. I told her that there was no woman there. I was merely putting the glass away. She accepted that.

For many months, I had accepted that this observed change in her behavior and thinking was just a natural progression of Parkinson disease. This behavior does not present itself when she and I visit her neurologist. I sent him a note before our last visit. We talked about it at length when we were there last time.

We are in the midst of slight medication adjustments and a series of pathology tests to rule out any physiological problems that could cause symptoms such as these.

So far these are all negative which makes me a bit sad. She is in the minority of parkies that the disease affects her cognitive function.

It is now more important than ever to seize the good moments, live in the present and jettison the anxiety for the future.

Face the thing. Maybe the outcome can be changed. As a caregiver do not forget that you have greater knowledge of your loved one than the doctor does. Tell the doctor what you see. It will help to find a solution.

And don't forget to Carpe Diem!

Who are you?
Who, who, who, who?
Who are you?
Who, who, who, who?
Who are you?
Who, who, who, who?
Who are you?
Who, who, who, who?

— *Peter Townsend*

The Saddest News

> Or what woman, if she had ten drachma coins, if she lost one drachma coin, wouldn't light a lamp, sweep the house, and seek diligently until she found it? When she has found it, she calls together her friends and neighbors, saying, 'Rejoice with me, for I have found the drachma which I had lost.'
>
> *Luke 15:8-10*

In December of last year (2021) I purchased a chain of gold for Cheryl to put her 25 year wedding band and her engagement ring onto and wear as a necklace. She had complained for months that her rings were falling off her fingers. She wanted a chain to put them on.

The woman who waited on us at Effler's Jewelers smiled when I told her what we wanted. I told her to think high school and a senior ring on a chain. (The memory makes me smile. Cheryl is my high school sweetheart, my prom date, where I am home.) She tried it on and pronounced it good, maybe perfect. After a week or so she determined that the clasp was a bit too tiny for her numb and shaking hands to manipulate when getting it on and off her neck. We returned and the jeweler was able to attach a larger clasp. Later she discovered that she was able to ease it up over her head without unclasping it.

She unconsciously would touch her rings and put her fingers through the rings while the chain was around her neck. It would occasionally become tangled and knotted. With another trip to the jeweler I was trained to unknot delicate gold chains. (wooden tooth picks work great) The occasional dissension broke out about wearing it to bed at night. Eventually it was carefully placed in the special box that came from the jeweler originally. The placing in the box became a nightly ritual.

As time went on she added a couple other special rings that she had in her jewelry box. For the past couple of months she has been wearing it with four rings.

In October of this year (2022) they are lost. A few days ago as we were traveling somewhere, I noticed that she was putting on a different necklace and I asked her where her ring necklace was and she said, “It’s in my pocket.” I now suspect it was not but at the time I thought nothing of it.

I know that I should not feel guilty about the disappearance of the necklace but I do. I suppose it is the care partner, the 50 years of marriage partner, the help mate, the one who panics most when she falls, the one who is not losing their memory – in me. I feel like I have let her down. I have made it my job to keep track of her stuff and mine.

Tony! Don’t be a phony. Help us out her. THE NECKLACE IS GONE.

Carpe the St. Anthony Diem.

Update: The necklace is back. It was recovered from the chair she is sitting on. Moral of the story – Don’t make the disease harder than it is. Sometimes stuff just falls in the crack between the cushion and the arm of a chair. (Sorry Tony. You are not a phony.)

Carpe Diem.

Punding

I once found a little card entitled “The Art of Marriage” in Cheryl’s purse. As I unwrapped and unfolded the little package in her purse I was very aware of the fact that it was none of my business what she kept in her purse nor why she kept those things in there. Nevertheless, faced with various requests for help, like, I can’t find my black comb or I have lost my glasses, I try my best to keep up with how objects and things are pared up, associated together in her newly confused mind.

I am guilty of looking around through her stuff to help her keep track of her stuff. I have no other interest in her stuff. That is my defense when I am caught. So far so good. I have not been caught yet. She thinks I am really good at finding things. If you know who would think to look in the freezer for a comb or used Kleenex for example, then you know someone who is care giver to some person with some variety of dementia.

Punding is a term used by the Norwegians or Swedes to describe the activity of mindlessly sorting or aligning objects, often random objects, in a fashion known only to the person doing this. I believe the term means “blockhead” Swedish.

In Cheryl’s case this behavior manifests as organization of articles and documents in preparation for a meeting or some other activity. She ran the early computer tech program at Nativity School when our children went there. Having no educational background caused her to be constantly looking to others who did, attending meetings and reading articles. She was excellent I am sure simply because she was aware of her weaknesses. She also helped her mother send cards and notes to family and friends to thank or take note of various occasions such as birthdays, holidays, anniversaries, graduations or merely an invitation to dinner. To this last Cheryl has kept many thank you notes from her mom for Sunday dinners over the years.

She gets these out and sorts, re-reads, thinks about her mom and shows them to me as though she received it in the mail today. Often she will say, I got this card from Mom. Or I got this Christmas card from (whomever).

She collects these in various clumps and collections. Some are in manila envelops. Some are in small gift bags. Some are collected in stacks with a rubber band around them. Some are in stacks held together by spring clips. Sometimes they may make some sense to me, sometimes they make no sense. No chronology. The collections can be totally random.

As she looks at the cards she reminisces about the old times. I used to point out that she was looking at a five year old Christmas card. I find that unimportant to do now. The activity is totally harmless. Late in the evening she is amenable to “I can help you with that tomorrow. Let’s go to bed and rest so we are more alert to work on that.” And we trundle off to bed tired from another day.

Carpe Diem.

The Black Comb

Sometimes things will get punded into oblivion for awhile. The black comb fell into this category a few days ago. The punding behavior will occur at random.

In the morning after its usefulness of removing tangles and bed head, the black comb generally goes into the purse of many pockets for safe keeping.

A few days ago the purse of many pockets was emptied out into various other places throughout the bedroom and maybe elsewhere. The black comb which is not a stand out when laying on the dining room table has been placed in a dark corner to remain safe.

Gone for now. It will be a distraction until it has been recovered.

(update – Black combs are almost invisible against the black carpeting in our car. The comb is back.)

Range of Emotion

From the perspective of care partner, there is a wide range of emotion that each day can give rise to. Personality is formed early in life and life situations do not change that fact. If your intrinsically cynical of life situations there are a lot of snarky comments that just come out in frustration. I do wish that I did not say a lot of things out loud but it is often too late. It is a real stresser to think about every comment before commenting or not commenting. No commenting at all is interpreted as disapproval which must be a default in her mind.

In that same vein if I misjudge the strength needed to close a cabinet door or miss the height needed to put a plate away after removing it from the dishwasher, Cheryl will interpret that as anger when in fact it might be incompetence. Incompetence is a fact but alas it is not an emotion.

The whole Parkinson thing means that I need to tread lightly. Treading heavily is interpreted differently. Upon occasion I will take a deep breath and exhale rapidly. Cheryl interprets this as a disappointed sigh and she immediately wonders what she did wrong to make me disappointed. Even the tiniest body language might be interpreted as something entirely different than what was meant.

It can be exhausting.

Conversational Receptiveness and Dementia

HEAR – Hedgey, Emphasis, Acknowledge, Reframing (from a recent study)

Communicative processes used to discover what is needed or desired by others in business or other walks of life work well with loved ones experiencing dementia and related memory issues. And while the single most important concept to remember is that short term memory loss affects every conversation, short term memory loss greatly affects attention span. Keep it short, keep it kind and keep it simple.

Here are some tips from an article in Psychology Today' website:

1. Consider the timing and mood of your recipient.
2. Check your own emotional level.
3. Be responsible for delivering clear communication.
4. Consider using I-messages to avoid blaming or putting others on the defensive.
5. Be a good listener (attentive) when receiving a communication.

And here are more from the Social Care Institute for Excellence website in UK:

Their focus is providing professional care to Alzheimer's patients and those dealing with other sources of dementia. Their techniques are good to understand for non-professional care givers. I use this list to think about and discern how better to help Cheryl.

- Minimize background noise
- Relax
- Think about how the person may be feeling
- Always introduce yourself
- Greetings or 'verbal handshake'
- Physical approach
- Be aware of emotions and touch
- Identify the emotional state of the response
- Don't be shy from tears or laughter
- Say what you think the other feels
- Keep it simple
- Use the person's name often
- Use visual aids and prompts
- Confirm understanding

Minimize background noise – I have noticed that Cheryl is easily distracted by almost anything that passes into her line of sight. I have noticed that Cheryl is unable to do two things simultaneously such as talk to someone and keep walking. I have noticed that Cheryl is unable to follow a conversation if two people talk animatedly about some topic in rapid succession or over the top of each other. I have noticed that Cheryl is unable to interpret words spoken with a different lilt or accent other than Midwest Cincinnati. I have noticed that she no longer watches any of her favorite shows on TV.

Relax – I struggle with relaxing and letting go for a bit if she is out of my sight. As her disease progresses and I see her falter with balance issues, stumbling gait and postural difficulties, my anxiety about her future (and mine) often comes through in my voice. I may say things or express opinions that can easily interpreted as rude, pedantic and egotistical. For those times I apologize to her and you.

Think about how the person may be feeling – I do not do this enough. It is easy from the outside to forget that the person is not the disease. Parkinson seems to make this harder because in one moment she will be "fine" and in the next she will be "off" - not necessarily physically off, mentally off and physically fine. I find this confusing and my default is not "she's confused – help her".

Always introduce yourself – Most of the time I do not need to do this. I can understand that it may be important for a professional to do this. Occasionally Cheryl is unsure of who I am. Mostly this occurs in the evening if she experiencing a bit of Sundowning. (Sometimes I am "that guy who brings the pills") Sometimes I tell who I am if I think she will accept it. Sometimes I leave it alone. The important thing is to not be insistent that she is wrong about who I am.

Physical approach – I have noticed that Cheryl startles much more easily than she did before Parkinson (bP). This comes in many forms visually and audibly but the important thing is to not surprise her. Surprises often lead to backing up and falling down which is her usual method of falling. She will move away suddenly from the perceived surprise.

Be aware of emotions and touch; identify the emotional state of the response; do not be shy of tears or laughter – I think these fit together as emotional response to conversation. Sometimes to me it is surprising that she will have tears about telling you that Laurencia is going to Ohio State University. I can understand that talking about her deceased mother will cause tears. Nevertheless it is important to understand that a person suffering with Parkinson may have her emotions very close to the surface. Try to remain calm but it is okay to "have a moment" and be with her. One memory often elicits another more tender memory and things tumble downhill quickly.

Keep it simple; use the person's name often or the other person's name if telling a story; use visual aids and prompts – pictures of children; confirm understanding – I have noticed that Cheryl may lose the thread of any story or conversation easily. She will not indicate in any way that she has lost track of what you are telling her. You may detect that she has lost it by some response that she makes. Simply reiterate some part of the story to help her recall. Do not get bogged down in correcting her mistaken thinking. Do not raise your voice to emphasize the correct story, time of day, holidays coming up, time of the year or who is coming to dinner. She will not remember but she will think that you are frustrated, angry or disappointed and respond with – I'm sorry.

Finishing - Just as you prepared to start a visit and conversation, so you must think about how you will bring it to a close. When you are leaving the our home, make sure you say goodbye. Cheryl may think that you are still here, perhaps in another room. This may cause confusion or anxiety later. Ensure you have her attention, smile, and let her know you enjoyed your time together and the conversation. Shaking their hand or hugging her is a common gesture which gives her a strong clue you are leaving. Leave her reassured and let her know you look forward to talking again.

https://www.scie.org.uk/dementia/after-diagnosis/communication/conversation.asp

https://www.psychologytoday.com/us/blog/healing-sexual-trauma/202008/5-essential-strategies-effective-communication

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Love

Love is stronger and different than our younger years. I am unsure of what that means but Cheryl is and always will be my existence. When we vowed to each other many years ago and codified our love we did not imagine a long term chronic disease. But then, most would not.

A blogger in New Zealand wrote this:

> *Acts of service, or perhaps my interpretation of it, is saying 'I love you' without saying it in words. While it is still lovely to hear those words the 'Acts of Service' are also powerful. They can be simple things like coming back into the bedroom after doing my morning exercises to find that – even half asleep – he has turned over and put the heat pump on to warm the room up for me. It is having him prepare dinner – even if it is just heating up some soup – when I need to sit down because of my current injury. It is putting the jug on and making a cup of tea for me while I shower. So many ways that we might do things for each other that might be seen just as a task to be done, but that if considered can be seen as that important 'I love you' without words.*
>
> *Next time someone does something for you, no matter how small, consider that they are not just carrying out a task, but doing so from the heart and showing that they care. As we move through the years on this Parkies journey, those Acts of Service may become more significant and those that we as people directly affected by this condition can do may seem less significant. However, if they are done with love, no matter whether large or small therein lies their significance.*
>
> *(2022) Kiwipommysue --My journey with Parkinsons*

From an early blog entry: What is Love?

What is love? - It can be many things. In the darkness of the night, perhaps it is patience. With little sleep comes paranoia, delusions and confusion. Love is staying awake to protect her, so she can sleep.

What is love? - Delusions come and are temporary. Love is a lifetime.

What is love? - It is simply putting someone else first. Yourself second.

What is love? - It is a mental state. It is more than physical. It is a devotion. A consuming ideal of dedication to another person's well-being. Words provide little justice to the state of love.

What is love? - It is not that giddy giggly feeling inside when you see the one you love, that is prescient to the knowledge that you are both here, together in the state of love.

What is love? - Love is a collection of feelings too complex and too simple for an easy description. It is a communion of emotions and actions. It is bazaar in its entanglements. It is a devotion to someone not you.

What is love? (a solution to the search for meaning in life perhaps.)

A Kiss to Awaken

I kiss her awake in the morning. It seems kinder than other ways. A little smile appears. Is it working? I ask.

The smile becomes a smirk. No. She replies. I leave to return later and try again.

She sleeps some more. I know that because I hear gentle snoring from the other side of the bedroom door.

And then I hear water moving through the pipes. She is alert . Getting cleaned up a bit.

The door opens. She is up. My heart leaps. It's a new day. A new beginning with less sun than desired perhaps but bright nevertheless.

I smile and plan breakfast.

Love Stories make Me Cry

I don't know why that is. They just do. They are not sad but some are. Life long love is precious. Some say that it is rare. Perhaps what makes me tear up is the fact that many people do not find love that lasts for a lifetime. Perhaps an inner joy in me appears when I discover a story like ours. Perhaps my tears are tears of joy for I cry at weddings and births too.

In the Fall/Winter Miamian (The magazine of Miami University) is a wonderful love story. Many Miami University grads met their life partners there while in school Oxford, Ohio. I imagine this is true of many university campuses but at Miami it is legendary. The story is about two people who met at a basketball game but did not know each other. They were set up by friends and began to date. During this time she noted that they could get a one hour PE credit for taking a social dance class. He did not want to do that but she insisted with, “If you’re going to date me, we will do this.” Later as they found out that they were in different sections of the class, she wanted to drop the class because it was not what she wanted it to be. He responded with, “If you’re going to date me, you are going to take this class.” The woman teaching the class allowed them to take their final exam together. It was a waltz. It was a metaphor for the rest of their lives.

Today she is suffering with Alzheimer's disease. And he is her caregiver. As time progressed she needed more care than he was capable. As he was moving her into a facility to care for her better the pandemic struck the U.S. The facility was about to lock the doors to curtail the spread of the virus to their residents. Could he move in with her? Yes. He has moved in with her to the assisted living facility to be with her throughout this Covid-19 pandemic. They locked the doors to the facility to stop the spread. True love.

I wonder about our future with Parkinson’s disease. As time progresses I notice that my life partner struggles with many of the simple organizational tasks associated with day to day living. I have taken over many of these, most of which fall into the category of chores – laundry, cleaning, cooking and the like. I wonder if it might have been better for me to not assume some of these tasks. It is not that I mind doing them but I have taken many of the daily routine tasks away from Cheryl and she has little of the daily routine chores to help her organize time during the day.

As it is, I am able to keep up with daily living chores. But I cannot resist looking towards the future and wondering about what is next.

In addition to being a movement disorder, Parkinson’s seems to destroy in some people the ability to perform parallel tasks. Cheryl has filled her days that I have removed the chores from with a task that her mother used to perform for the family. Elaine used to keep track of and send an appropriate card to children and couples on the recognition of their birthdays and anniversaries. Intermingled with this was additional well wishes for illness, deaths and other life events. It is somewhat unique in her extended family as I have noticed no one else doing this. Facebook has the unintended consequence of reducing within a family notes, cards, phone calls and other intimate connections. (Perhaps a good new year resolution is to get off Facebook and onto the phone or email or snail mail to reconnect.)

I have digressed. The simple act of keeping an address list up-to-date and maintaining a calendar with birthdays, anniversaries, deaths or other dates is confusing to one who is loosing her ability to remember which pocket of her purse holds the chap stick she put in there moments before. I help her and have helped her a bit around the fringes but I am resistant to take over this task in its entirety. It is something she wants to do. It seems to be something she likes to do. It is something that frustrates her greatly upon occasion. It is something that derails her objective when she discovers an incorrect address or thinks she has discovered an incorrect address because she has remembered an address from "auld lang syne". When this happens one must stop and wait for the correct address to appear from the email inbox – or text message stream which is a variety of the same thing.

This is merely an example of a deteriorating brain and I wonder if I will be able to keep up with her needs into the future. The husband of the couple interviewed in the Miamian recognized that he was unable to tend to her needs completely and decided assisted living was the answer. His wife has Alzheimer's which is by my perception much more debilitating than the slow progression of Parkinson's disease dementia but will I recognize when I am unable to take care of her on my own?

Our love is here to stay. Their love is also. I will always cry when I find a love story of two people devoted to each other for life.

Parkinson's disease sucks. I hope I can recognize where it is sucking us toward.

[i carry your heart with me (i carry it in]

By E. E. Cummings

i carry your heart with me (i carry it in
my heart) i am never without it (anywhere
i go you go, my dear; and whatever is done
by only me is your doing, my darling)
                                                      i fear
no fate (for you are my fate, my sweet) i want
no world (for beautiful you are my world, my true)
and it's you are whatever a moon has always meant
and whatever a sun will always sing is you

here is the deepest secret nobody knows
(here is the root of the root and the bud of the bud
and the sky of the sky of a tree called life; which grows
higher than soul can hope or mind can hide)
and this is the wonder that's keeping the stars apart

i carry your heart (i carry it in my heart)

In a different discussion with my cousin Frank's widow, Linda revealed that Frank kept a book by E. E. Cummings on his desk. I vaguely recalled the Cummings was a poet but I was not sure so I looked him up on the world wide wait. I was proven correct and I went to a poetry website that I occasionally visit. Searching for some of his work this was the first poem displayed. (I think Frank was talking to me.) Thanks Linda and Frank. I have found another poet who speaks to me.

Anger

I have a small note book that I use when I am away from my computer keyboard. I prefer to type and allow the word processor to help with things like spelling. As a result I am not good at transcribing notes.

These notes are from that notebook;

Anger is a very strong emotion as this disease steals any reason and organizational skills from Cheryl. It is very hard for me to keep the distress from my voice so that she is not upset. But it seems that if I take the time and consciously slow myself and think patience, I can help with not upsetting.

- I have no interest in the oddball things she wants to do at night in her office (punding).

- I might go nuts without time for me.

- I dislike not finding the ability to do things with her.

- She is different when other people are around.

- I can be elsewhere when others visit.

__________ ~~ _________

Recognizing anger that arises in dealing with a chronic disease for what it is – a combination of frustration, disappointment and grief – is the first step in recognizing how to get relief from the stress that it causes in the care partner and the friction that can happen in the immediacy of the moment.

__________ ~~ _________

Sadness

Sadness about life and our situation constantly creep into my daily thoughts. I often find myself thinking about how to do things and react to situations better. Sometimes I curse the gods and fate. Lot's of my blog entries are written so that I can hold my thoughts up to the light and gain some acuity as to what would have been a better reaction. Some of them are merely whining about life. It is tough work.

How Big are You

> *Author and futurist Robert Anton Wilson on the size of a person:*
>
> ***"You are precisely as big as what you love and precisely as small as what you allow to annoy you."***
>
> *Source: Nature's God*
>
> *— from James Clear's email*

It spoke to me. Deeply.

I do feel small when I allow Cheryl's disease to become her. It boils over into anger and guilt. I forget often that she is not her disease.

She has been getting physical therapy to help her with movements like getting out of a chair. Sit to Stand is the notation on the PT's notes. This motion is natural to non-PD people. One does not even think about the mechanics of it. Cheryl has to think and remember the sequence of moves. Depending on the time of day and how she is feeling, thinking and memory are difficult. So she simply cannot remember how to get out of a chair.

When she has fallen and when she falls it is always backwards. I encourage her to lean forward at her waist and push off the chair as the PT told her. Nose over toes (N-O-T) is the mantra. But in view of anything, walker, table, person, nearby grab bar or whatever grip, grab and pull easily win over N-O-T. I encourage by telling her where to put her hands and how to position her body. She responds with don't-tell-me-what-to-do anger. I respond in kind and then feel bad because I was to her unkind.

I love her dearly (big). I am annoyed with her disease (small) and I allow it to be her (smaller).

My personal reason for writing this is to hold that idea up in the light and discern how to be better next time. I am grateful for all the next times even though anger anxiety and anxiousness might creep back in. It is hard work and I am not that good at it.

Time to meditate and ponder with deep sagacity.

… From a blog entry in August of 2022. Carpe Diem

Melancholy

A sadness about things that we used to do creeps in once in a while. Grief, melancholy and nostalgia are all mixed up sometimes. When you feel the need to roll in it for awhile, ask Alexa to place a little country western music for a bit. Play '70s rock to get out that mood.

Apathy

This is not a constant in Cheryl's PD. Over time since we bought the big new bed she sleeps later- probably but not so late that she seems to have given up on life. Her focus is narrowed over time.

There are good days and bad days of course and we all have meeah days when little is accomplished or sought after. *Carpe the Diem.*

Grief

We had a Moment

It was early afternoon. It was about an hour after she had taken a dose of meds. She was standing at the kitchen sink. Her dyskinesia was noticeable. Her conversation was anxious.

She was worried about what was going to happen with the occupational therapist … I think. I tried to convince her to sit and rest for a bit until we had to go there.

I went to putz in my office. Alexa was playing Rod Stewart old standards from his Great American Songbook album. Time after Time came on "… so lucky to be loving you" a waltz or foxtrot. I asked her if she wanted to dance. The song was a favorite of ours. I turned it up a bit and coaxed her into the space between the dining and living area. She put her arms up around me and I did the same. We hugged and danced in place. She burst into tears as some Parkinson's emotions took over.

Me too. We took a moment to feel a little sad about our current situation. We took a moment to let the emotion wash over us. At that point in time life was overwhelming. We had to let it be overwhelming in order to move forward with life some more. It is okay to lament life for a bit.

The song ended and we sat in the living room. Rod started singing, "I see fields of green, red roses too…" She watched some of the pictures go by on the Frameo that Anna gave her a couple years ago. She cried a little bit more and enjoyed the nostalgia. And then we were ready for life again.

Sometimes grief for the loss of things that once were surfaces when it is not expected. Embrace the emotion and it is gone again. Fight it and it will become something less satisfying like melancholy or apathy.

Find all the tender moments you can. Carpe Diem.

Treatment drugs (some tossed as ineffective)

Drug treatment for Parkinson disease is widely varied. Basically the brain is making less dopamine than it needs to operate properly. Symptoms are relieved and even alleviated when this dopamine is recovered or replaced somehow. Somehow is key because not all parkies react to the drug therapy in the same fashion. (What a surprise. We are unique in our individuality.)

Organization of the drugs – in a series of boxes for a week (add pics and description)

Discovery of how things work – lots of reading (more descriptive)

Carbidopa/Levedopa (Sinemet)

From www.drugs.com or https://medlineplus.gov : (scary shit) – Cheryl takes the 25mg/100mg tablet on an every-three-hour schedule throughout the day.

What is carbidopa and levodopa? Carbidopa and levodopa is a combination medicine used to treat symptoms of Parkinson's disease, such as stiffness or tremors. Carbidopa and levodopa is also used to treat Parkinson symptoms caused by carbon monoxide poisoning or manganese intoxication. Carbidopa and levodopa may also be used for purposes not listed in this medication guide. (restless leg syndrome)

Side benefits:

Get emergency medical help if you have signs of an allergic reaction: hives; difficult breathing; swelling of your face, lips, tongue, or throat. Carbidopa and levodopa may cause serious side effects. Call your doctor at once if you have: uncontrolled muscle movements in your face (chewing, lip smacking, frowning, tongue movement, blinking or eye movement); worsening of tremors (uncontrolled shaking); severe or ongoing vomiting or diarrhea; confusion, hallucinations, unusual changes in mood or behavior; depression or suicidal thoughts; or severe nervous system reaction--very stiff (rigid) muscles, high fever, sweating, confusion, fast or uneven heartbeats, tremors, feeling like you might pass out.

Some people taking carbidopa and levodopa have fallen asleep during normal daytime activities such as working, talking, eating, or driving. Tell your doctor if you have any problems with daytime sleepiness or drowsiness.

You may have increased sexual urges (still hoping for this one), unusual urges to gamble, or other intense urges while taking this medicine. Talk with your doctor if this occurs.

You may notice that your sweat, urine, or saliva appears dark in color, such as red, brown, or black. This is not a harmful side effect, but it may cause staining of your clothes or bed sheets.

Common side effects of carbidopa and levodopa may include: jerky or twisting muscle movements; headache, dizziness; low blood pressure (feeling light-headed); sleep problems, strange dreams; dry mouth; muscle contractions; or nausea, vomiting, constipation. This is not a complete list of side effects and others may occur. Call your doctor (if mystery shit happens.)

The Controlled Release CR version of this combination

The CR version of carbidopa/levedopa has all the same side affects with the added benefit of being delivered erratically to the patient. This substance is absorbed by the body in the upper gut. Absorption is affected by various foods. Ingestion of protein directly effects the usefulness of c/l intake.

Ondansetron

Ondansetron is used to prevent nausea and vomiting caused by cancer chemotherapy, radiation therapy, and surgery. Ondansetron is in a class of medications called serotonin 5-HT3 receptor antagonists. It works by blocking the action of serotonin, a natural substance that may cause nausea and vomiting.

Ondansetron comes as a tablet, a rapidly disintegrating (dissolving) tablet, film, and an oral solution (liquid) to take by mouth. The first dose of ondansetron is usually taken 30 minutes before the start of chemotherapy, 1 to 2 hours before the start of radiation therapy, or 1 hour before surgery. Additional doses are sometimes taken one to three times a day during chemotherapy or radiation therapy and for 1 to 2 days after the end of treatment. Follow the directions on your prescription label carefully, and ask your doctor or pharmacist to explain any part you do not understand. Take ondansetron exactly as directed. Do not take more or less of it or take it more often than prescribed by your doctor.

If you are taking the rapidly disintegrating tablet, remove the tablet from the package just before you take your dose. To open the package, do not try to push the tablet through the foil backing of the blister. Instead, use dry hands to peel back the foil backing. Gently remove the tablet and immediately place the tablet on the top of your tongue. The tablet will dissolve in a few seconds and can be swallowed with saliva.

Cheryl takes the ODT version of this. There is a study that was done showing that the ODT version of this drug has special benefits for parkies. We discovered this after Anna had taken Cheryl to the ER with a case of uncontrolled nausea. The ER folks gave her 4mg ODT. Anna noted that you could the the stuff work as Cheryl's face relaxed with its action.

Ondansetron may cause side effects. Tell your doctor if any of these symptoms are severe or do not go away: headache; constipation; weakness; tiredness; chills; drowsiness

Some side effects can be serious. If you experience any of the following symptoms, call your doctor immediately or seek emergency medical treatment: blurred vision or vision loss; rash; hives; itching; swelling of the eyes, face, lips, tongue, throat, hands, feet, ankles, or lower legs; hoarseness; difficulty breathing or swallowing; chest pain; shortness of breath; dizziness, light-headedness, or fainting; fast, slow or irregular heartbeat; agitation; hallucinations (seeing things or hearing voices that do not exist); fever; excessive sweating; confusion; nausea, vomiting, or diarrhea; loss of coordination; stiff or twitching muscles; seizures; coma (loss of consciousness)

Ondansetron may cause other side effects. Call your doctor if you have any unusual problems while you are taking this medication.

Have a friend call if you are in a coma. It is interesting that some of the recognized side effects are that which the drug is intended to solve.

Since discontinued in Cheryl's regimen. She seems to have no stomach issues.

Entacapone

(Al Capone's wife – Enta) Entacapone is an inhibitor of catechol-O-methyltransferase (COMT). It is used in combination with levodopa and carbidopa (Sinemet) to treat the end-of-dose 'wearing-off' symptoms of Parkinson's disease. Entacapone helps the levodopa and carbidopa work better by allowing more of it to reach the brain, where it has its effects.

Entacapone comes as a tablet to take by mouth. It is taken with every dose of levodopa and carbidopa, up to 8 times a day. Entacapone may be taken with or without food. Read your prescription label carefully, and ask your doctor or pharmacist to explain any part you do not understand. Take entacapone exactly as directed. Do not take more or less of it or take it more often than prescribed by your doctor.

Entacapone helps control the symptoms of Parkinson's disease, but it does not cure it. Continue to take entacapone even if you feel well. Do not stop taking entacapone without talking to your doctor. Stopping entacapone suddenly may make your Parkinson's disease worse and could have other dangerous effects. Your doctor probably will decrease your dose gradually if necessary.

Entacapone may cause side effects. Tell your doctor if any of these symptoms are severe or do not go away: dizziness; diarrhea; upset stomach; movements you cannot control; stomach pain; drowsiness

If you experience any of the following symptoms, call your doctor immediately: difficulty breathing; hallucinations; high fever; confusion; muscle stiffness; weakness with or without a fever

If you experience a serious side effect, you or your doctor may send a report to the Food and Drug Administration's (FDA) MedWatch Adverse Event Reporting program online (http://www.fda.gov/Safety/MedWatch) or by phone (1-800-332-1088). Anyone can report anything. Beware.

Donepizil (Cholinesterase inhibitor)

Donepezil is used to treat dementia (a brain disorder that affects the ability to remember, think clearly, communicate, and perform daily activities and may cause changes in mood and personality) in people who have Alzheimer's disease (AD; a brain disease that slowly destroys the memory and the ability to think, learn, communicate and handle daily activities). Donepezil is in a class of medications called cholinesterase inhibitors. It improves mental function (such as memory, attention, the ability to interact with others, speak, think clearly, and perform regular daily activities) by increasing the amount of a certain naturally occurring substance in the brain. Donepezil may improve the ability to think and remember or slow the loss of these abilities in people who have AD. However, donepezil will not cure AD or prevent the loss of mental abilities at some time in the future.

Donepezil may cause side effects. Tell your doctor if any of these symptoms are severe or do not go away: nausea; vomiting; diarrhea; loss of appetite; weight loss; frequent urination; difficulty controlling urination; muscle cramps; joint pain, swelling, or stiffness; pain; excessive tiredness; difficulty falling asleep or staying asleep; headache; dizziness; nervousness; depression; confusion; changes in behavior or mood; hallucinations (seeing things or hearing voices that do not exist); abnormal dreams; red, scaling, itchy skin.

There are more but it looks like the same list of scary stuff that all these drugs have. Basically if you notice strange things while pooping or peeing call the doctor.

Seraquel

Quetiapine – From WebMD.com – This medication is used to treat certain mental/mood conditions (such as schizophrenia, bipolar disorder, sudden episodes of mania or depression associated with bipolar disorder). Quetiapine is known as an anti-psychotic drug (atypical type). It works by helping to restore the balance of certain natural substances (neurotransmitters) in the brain. This medication can decrease hallucinations and improve your concentration. It helps you to think more clearly and positively about yourself, feel less nervous, and take a more active part in everyday life. It may also improve your mood, sleep, appetite, and energy level. Quetiapine can help prevent severe mood swings or decrease how often mood swings occur.

So why is she taking that you ask? Quetiapine has an off label use for helping one to sleep. In some patients it causes drowsiness. In Cheryl it some times causes drowsiness.

… from Medlineplus.gov – Studies have shown that older adults with dementia (a brain disorder that affects the ability to remember, think clearly, communicate, and perform daily activities and that may cause changes in mood and personality) who take antipsychotics (medications for mental illness) such as quetiapine have an increased risk of death during treatment.

The off label use for sleeplessness is well below the anti-psychotic treatment dosage.

Rivastigmine

Good for memory but it makes you puke. Cheryl discontinued this one after spending Sunday afternoon kneeling on the bathroom floor waiting for puke that never came.

Midodrine

Low blood pressure medicine. This seems to work for Cheryl most of the time. Her fainting spells went away after she started taking this and the dosage was adjusted. The dosage was adjusted so that she only takes three of these a day.

Midodrine is used to treat orthostatic hypotension (sudden fall in blood pressure that occurs when a person assumes a standing position). Midodrine is in a class of medications called alpha-adrenergic agonists. It works by causing blood vessels to tighten, which increases blood pressure.

Midodrine comes as a tablet to take by mouth. It is usually taken three times a day during the daytime hours (such as morning, midday, and late afternoon [before 6PM]) with doses spaced at least 3 hours apart. Take the last daily dose of midodrine before an evening meal and at least 4 hours before bedtime.

Take midodrine during daytime hours when you need to be upright. Avoid taking a dose when you will be lying down for any length of time. Also talk to your doctor about how to position yourself when you are lying down. Your doctor may tell you to raise the head of your bed when resting or sleeping.

B6

Deficiency of this vitamin can cause peripheral neuropathy. Cheryl was taking this because she thought she might be experiencing peripheral neuropathy. People with Parkinson's sometimes experience weakness, numbness, and pain in their hands and feet. Cheryl often has numbness in her fingers.

Recommended dose to females over 50 years: 1.5 mg/day Too much can cause peripheral neuropathy so maybe not take any extra. It is in a lot of foods. Discontinued as a separate supplement.

B12

Vitamin B12 is a nutrient that helps keep your body's blood and nerve cells healthy and helps make DNA, the genetic material in all of your cells. Vitamin B12 also helps prevent megaloblastic anemia, a blood condition that makes people tired and weak. Recommended dose – Adults 2.4 mcg (millionth of a gram) Discontinued as a separate supplement.

Both B6 and B12 are part of any general multivitamin tablet.

Multivitamin

Things mom said you needed.

Pantaprozole

Gastroesophageal reflux disease (GERD) occurs when stomach acid repeatedly flows back into the tube connecting your mouth and stomach (esophagus). This backwash (acid reflux) can irritate the lining of your esophagus – causing erpy burpies. There are a bunch of different meds to help this OR do not eat anything or at least very little after 7 PM. Cheryl does both.

Many people experience acid reflux from time to time. However, when acid reflux happens repeatedly over time, it can cause . Most people are able to manage the discomfort of with lifestyle changes and medications. And though it's uncommon, some may need surgery to ease symptoms…. *Mayo Clinic.*

She has since discontinued this and takes Omemprazole which is a different variety drug which is OTC.

Stool softeners (and occasional laxative)

To keep from getting stuffed up – a common symptom of Parkinson is your bowels not working so well. It is also something that people rarely talk about in public with others. Having an impacted bowel will terminate your existence, so perhaps it is good to talk about it, just maybe not over dinner.

Melatonin

To fall asleep – works sometimes and sometimes not. Placebo effect is strong in any chronic disease patient. Placebo effect can be ignored at will.

Glucosamine

This is the magic cure for crappy knees. Cheryl inherited her mother's crappy knees. Since parkinson appeared and we moved to a one floor plan condo-minimum, she has lost approximately 35 pounds and there are no steps to traverse to the bedroom. She has not complained about her knees for years.

Biotin

She cuts her hair very short and worries about hair loss. This magic elixir is supposed to help with hair loss.

Amantadine

Amantadine is used to treat the symptoms of Parkinson's disease (PD; a disorder of the nervous system that causes difficulties with movement, muscle control, and balance) and other similar conditions. It is also used to control movement problems that are a side effect of certain medications used to treat Parkinson's disease. Amantadine extended-release capsules (Gocovri) are used along with the combination of levodopa and carbidopa (Rytary, Sinemet) to treat "off" episodes (times of difficulty moving, walking, and speaking that may happen when other medications wear off) in people with Parkinson's disease. It also is used to prevent symptoms of influenza A virus infection and for treatment of respiratory infections caused by influenza A virus. Amantadine is in a class of medications called adamantanes. It is thought to work to control movement problems by increasing the amount of dopamine in certain parts of the body. It works against influenza A virus by stopping the spread of the virus in the body.

This particular substance produced wild hallucinations in Cheryl. She stopped taking it abruptly after a very bad night in Saginaw Michigan. We were traveling to meet some friends and stopped overnight in Saginaw. We cut our trip short and returned home. Who could have predicted an influenza med would cause so much trouble.

Desperation for a solution

Tums seem to generally work well for stomach upset. Sipping water also helps. Sipping lemon ginger tea helps too.

And there are all sorts of YouTube experts that can help cure Parkinson's disease. It is after all a chronic disease with no known cause (idiopathic) although it is suspected to be linked to pesticide chemistry and other things like concussion, there is no big AHA in the scientific community that even slightly resembles a smoking gun of a cause. Lawyers are hoping to get a direction to point their lawsuit in.

Gummies

See Mary Jane.

Mary Jane

Cannabis cures everything. “Everyone” knows this to be true. It probably works similar to alcohol, in the fact that it does not alleviate symptoms but after a certain amount of ingestion one no longer cares about the symptoms. Still skeptical of any evidence of its usefulness but the relaxation effect of the active chemicals derived from hemp (CBD oil) and cannabis (THC and CBD) do seem to help some people. Whether that effect is placebo or real is unknown (so far). There are actual scientific studies.

Luminaloe

See B6 and B12. This is a food supplement. Mucilage probably works as well. As with everything there is a YouTube video.

Where we are Now:

The schedule is 7AM

- 2.5 c/l & 1 entacapone; 1 midodrine; 1 Glucosamine; 1 biotin; 1 omemprozol

10 AM

- 2 c/l & 1 entacapone

1 PM

- 2 c/l & 1 entacapone; 1 midodrine

4 PM

- 2 c/l & 1 entacapone; At 5 PM - 1 midodrine

7 PM

- 1 c/1 & 1 c/l CR for help overnight.

Bedtime

- 1.5 quetiapine; 2 stool softeners; 1 donepezil (5mg); 1 melatonin (5mg)

This seems to work for Cheryl. Her episodes of delusional behavior, although not gone, seem less so.

Daily Log Notes

I started to write down a daily log with more conviction in May of 2022. Cheryl was having more and more trouble with sleeping through the night. It was affecting me greatly and I was becoming Mr. Cranky Pants during the day. (I'm always cranky in the middle of the very early morning hours.)

I discovered that it was/is hard to do this on a consistent basis. In about October I found myself making notes in the evening before going to bed myself. Maybe that works for me.

5/1/2022

slept late – 10AM | visit David – feeling busy

5/2/2022

up for 7AM meds | bfast 8 am | napish – 10:30am

5/3/2022

up for 7AM meds | tired but moving all day | 12PM exer. Class

5/4/2022

up for 7AM meds | lay down for a bit | french toast bfast | Wobbly but cleaning Kitchen | evening fell bkwrds in bedroom – no bad injury || bed at 10:45 PM – confused

She describes her bedroom fall as freezing but it is hard to get through her loss of correct words and disjointed thoughts

5/5/2022

up 7 f/meds | no leaks overnight | confused about what's happening even with notes | UHC (United Healthcare) nurse in mid-afternoon visit | pizza dinner w/no upset stomach

5/6/2022

up 7am meds | incontinent @ 4am | chg & sleep | coffee cake bfast | bed at 10:15pm back up at 11:30pm – can't sleep

5/7/2022

up until 1am | slept ?? until 2:15 am| wake until 4am | asleep until 9:30am | 7am meds at 9:30am | incontinence | *this will be a long day* | big BM in afternoon

I do not always ask about bowel habits. Generally constipation is a problem with parkies. Constipation is also associated with sleeplessness but there is only correlation no evidence of causality.

5/8/2022

Mother's Day | up at 3am w/severe leg & Hand cramps | about 15-20 minutes able to sleep again | strange conversation about kids/school/business | up at 9:30am (7am meds) skip 10am meds | some incontinence | o.j. and coffeecake | bed at 11PM

5/9/22

up at 7am | layed down for an hour or so | incon O/night | daily confusion | anxious & upset about Ron Miller death 10yrs ago | we danced at dinnertime

5/10/22

Cheryl's birthday | confusing conv abt dr. changing appt. time | notes from DR V – Cheryl OK conver./ new walker to help with falling/no new meds or schedule | confused aft 4PM meds | Pizza Party w/kids | pictures and celebrate | tired – to bed at 9:45PM

It is hard to keep a daily log. (I wrote to myself. There is a gap. All I can report is that our life must have been same enough that I lost interest for a few days.)

5/17/22

slept ok | dinner w/family at Willie's | up at 1:30am – bed at 3:30am

5/18/22

meds at 7AM | up at 8AM | (threw her underwear away)

5/19/22

slept ok | up for trip w/Barb Tyrin to visit with Diana @ Mapleknoll | story from Cheryl about Cottingham? | gone 10AM-3PM | nap when return | bed 10:30PM

5/20/22

Up at 2AM | inconsolable & tired | bathroom/toilet/brush teeth | naked | (me) went to sleep on sofabed 5:30AM | (me) up at 7am meds – laid down |up at 7:30AM

5/23 & 24/2022

up at 2:30AM – wrote todo list | poor sleep patterns last two nights | walked with U-Step walker approx 7/8th mile

5/25 & 26/2022

woke up (25) compl of severe pain in left hand and arm | up & dwn o/ngt |ibuprofen and cereal seemed to ease | Linda visits | (26) up at 2am & waffles | 10am snack breakfast | exercise class | **buy new bed**

5/27

up at 1:30A for cereal – life & dr. Ch. | up at 6:30a for toilet & meds | shower 9A |nap after 10A meds | bed at 11:30P

5/28

up @ 2a toilet | up @ 3A – complaint about congestion & stuffy nose; took off all clothes | fell asleep nude | up @ 8:30A for meds – pjs on – lay down | up @9 fr bfast | 10:30A showered

5/29

up til 4:30A | slept til 11:45A | meds schedule is really screwed up

5/30

bed @ 11P | fidgety up @ 2A | took off clothes | I slept on the sofabed in the living area.

6/1

Removed 1 Sinemet CR from her overnight – up once for toilet

6/2

Again removed one S/CR from her overnight – did not get up at all – incontinent early mornings

6/3

donuts for bfast ; fell in kitchen while standing ; rested in chair ; midodrine (1PM) early – 12pm

6/4&5

4 – walk at ferbank ; visit with David ; in bed 11pm ; leakage at 5:30AM up to fix ; slept till 10am

5 – 7am meds at 10 : waffles bfast ; max’s baseball game

6/6

slept overnight okay ; up at 7am meds ; ower @ 9:30 am & fell in shower – slid downhill : mat?- ordered mat ; about 9pm she fell in her office (bumped head on chair) ; bed 10:30pm

==> Fell twice in one day – a new first

6/7

7am meds ; change o/n pants 11:30pm & at 7am ; cherrios at 8AM

6/8

7am meds ; bfast b/berry pancakes at ~ 8:30am ; NEW BED TODAY ; fell in doorway after removing keys

6/9

call from Deb @ 8PM ; fuzzy headed thinking before bed – Debbie here – keeping shoes to go home – sleep here go home tomorrow ; in bed at 11pm ; up @ 12:40 to brush teeth ; back to bed & sleep to 7am meds ; leakage in AM

6/10

stomach upset w/10am meds ; clothes on at 1pm ; bed at 10:30pm ; up several times to toilet o/n 12/2/5 ; not awake at 7ambfast

6/11

asleep until 10am (she did not stir with alarm so I let her sleep) ; episode of feeling faint and nausea- used ondansetron ODT – layed on floor for a bit-then lounge chair – later after 1PM meds took nap (1HR) : seems agitated about cards – picked out quilt(s) ; incon overnight sleep til 10am : ?

[I am transcribing my note book on 9/30/2022. 2PM in the afternoon Cheryl is having some sort of odd mental disturbance – punding with her jewelry. Wants to write down who gets what when she is gone (her words).]

6/12

slept completely thru night(incon/noleaks) ; up 7am meds : lay down

– I slept pretty good too. Up 2x : pretty good day and no extra laundry ; start donepezil tomorrow ; bed after 11PM

6/13

started donepezil tonight ; slept until 10 am ; 7am at 10 am skipped 10 am dose ; installed new grab bar near shower ; bed at 9:30pm

6/14

12am to toilet ; up at 7am ; dry (slept on rgt side) ; no moves all night ; me – 12,2,5,6:50 – urinate

6/15

poor sleep ; up every 30 – 45 minutes until 3am ; slept til 8am ; ???

6/16

bed @ 11pm ; slept well ; up @ 7am

6/17

bed 10:45PM ; up at 5am toilet ; still asleep at 9am

6/18

bed @ 10:42PN : up 6:30am toilet meds ; laying in bed at 8am

(Who am I? - Cheryl | Who are you? Paul |… We've been married 50yrs. Happy Anniversary!) - an odd morning conversation

6/19

strange dream at 5am ; thought I was ill. ; up 2am toilet chg ; meds at 8:30am ; laid back down ; up at 10am

6/20

bed @ 9:45pm ; up at 5am toilet chg ; sleep til 8am – up ; bfast donuts ; lunch with frnds ; dinner w/frnds ; support grp 7PM

6/21

bed @ 10:15PM ; up at 8am ; slept thru ; bfast 8:30am cereal ; shower 10am

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This goes on and on and is boring reading. As I have commented here and there in my notebook it is hard to keep a daily log. A diary is not quite the same thing. In a diary the author often comments about feelings, emotions, spirituality.

In September I started to add my own impressions. During this time – May until November of 2022 – we had several discussions during her lucid periods during the day. We made a couple changes in her med schedule and a couple changes in her dosage.

She now takes Sinemet (25/100) 2.5 | 2 | 2 | 2 | 1 & 1CR – sch'd for 7, 10, 1, 4, 7 but often taken at 9, 11, 1, 4, 7 if she slept late. If she sleeps until 10AM she skips the second group of two pills. Entacapone is taken with the first four doses. Midodrine is taken with the first and third usually about 9am and 1pm and one by itself at 5pm. Donepizil is taken at bedtime whenever that is, typically 10-11PM. We have removed her ondansetron ODT for nausea. I hold it in reserve for if she complains about severe nausea. Pantaprozole for her GERD has been switched to an OTC medication Omemprazole which seems to be working well for her. Any evening upset stomach she treats with Tums.

She now rarely complains of nausea or stomach upset in the evening. – October 29, 2022

Lament

One more for the road is a line from an old song. Late at night Cheryl's conversation gets a bit strange. It has for some time now. It has a lot of names; sundowner syndrome, parkinson disease dementia, lewy body dementia, dementia. What it is called is unimportant. It would be important if there was a cure to one or several of these. There is not. The simple fact of memory loss and associated confusion has no cure. It also has no known definitive cause. It just is. It is idiopathic.

Louis Armstrong – sings this song. I really like the song. The sentiment to me always brings tears to my eyes. I do wish we were not here in our life together. I wish we were in Louis's world.

I see trees of green
Red roses too
I see them bloom
For me and you
And I think to myself
What a wonderful world
I see skies of blue
And clouds of white
The bright blessed day
The dark sacred night
And I think to myself
What a wonderful world
The colors of the rainbow
So pretty in the sky
Are also on the faces
Of people going by
I see friends shaking hands
Saying how do you do
They're really saying
I love you
I hear babies cry
I watch them grow
They'll learn much more
Than I'll ever know
And I think to myself
What a wonderful world
Yes, I think to myself
What a wonderful world
Ooh, yes

Most of the time, however, I am okay with the world as it is. I simply wish that I did not share it with Sam Parkinson.

After All this Time

It has been (and still is) a long journey. There are days when I am angry. There are days when I am sad. There are days when I really miss our old life. There are days when I just feel old.

But I still love her. I think what is most missed is just living life with each other. These days we live life with each other and Parkinson. Often she does not remember the life we are living.

I keep telling myself Carpe Diem. Seize the day, seize the moment. Quit worrying about what is coming or might come. Focus on now. And at the same time quit looking over your shoulder. Keep your memories, remember the good times, learn from the not so good times. And be gracious.

I do miss being younger.

Articles and Notes

When Caregivers Are Honest, It Makes Folks VERY Uncomfortable

Caregiving sucks, so quit trying to sugarcoat it.

By Ann Brenoff 08/04/2016 07:01am EDT | **Updated** August 9, 2016

A weakened version of the man I married was discharged a few weeks ago after a month in the hospital. My husband now gets dialysis a couple of times a week as an out-patient, sleeps a lot in between treatments, and in general feels pretty lousy served up with a regular side order of grumpy. I'm told that's par for the course.

In addition to being everything I was before — wife, mother, full-time working woman, family manager — I am now also his chief caregiver. I shop, cook and clean up after him. I make sure he takes his medicines when he's supposed to. I argue with doctors, visiting nurses, and insurance people on his behalf. He runs out of nothing, because I'm responsible for refilling everything. When he needs to go somewhere, I get him there. When he needs something done, I do it. There is no task too unpleasant, too distasteful, too "I-can't-believe-I'm-doing-this." I just do it, all of it, and I try hard not to think too much about it.

It's a role I didn't ask for, don't want, and frankly, kind of suck at. But being a reluctant caregiver is my issue, not yours. Your issue is that when caregivers talk frankly about their feelings, it makes you uncomfortable and then stupid things come out of your mouth. Want an example? When I say caregiving sucks, you tell me "no, you don't really mean that." But yes, yes I really do.

I've come to see this practice as caregiver-shaming and would like it if you'd please stop.

To start, you can stop telling me how I should be feeling. Stop telling me I shouldn't be angry. Stop saying there is something rewarding about what I'm doing because trust me, there isn't. And also, for the love of all things mighty and good: Please stop telling me how lucky I am. As one military caregiving wife I know says, "Sure I'm glad my husband came home alive. But he's in pieces, not whole. I don't get how people somehow think this makes me 'lucky?'"

If you could stop judging us for a minute, you might realize that every honest caregiver has moments of sheer rage and resentment. One woman I know goes down to her basement and screams into a pillow so her kids don't hear. Me? I prefer the shower, the one in the bathroom where the door still locks. Why can't a caregiver just say, "I really can't take this much more" without someone telling her she is wrong?

Caregivers feel sad, lost, and sometimes angry — very angry. Since I began writing about my caregiving experience, I have heard from caregivers who say they sometimes wish their patient were dead. "Then I could *just have a normal life," said one woman who's been caregiving for almost three years without a day off. Another woman I met cared for her own mother for seven years and now cares for a sick husband. She says, "It's like one died and I had an opening." Then she adds wryly, "I just can't catch a break. When is it my turn to live again?"*

Sometimes, we caregivers just need to let it all hang out. One woman told me how, when her husband was in the ICU hooked up to machines from every orifice, she blurted out "You did this to yourself." Sounds harsh, right? OK, that was me. Blaming the patient is a reoccurring theme for which caregivers are shamed. "Oh you don't mean that!" we are told. Actually, we do. At least in that minute in time, yes we really really do. As I asked my own sweet husband, "All those Cokes and Hershey bars? Did they taste good? Because now we are all living with the consequences of your eating them."

A caregiver friend — half my age and with twice my smarts — says that what she longs for most is a single day in which all the decisions don't fall to her. "It would be a mini-vacation," she said. She would also like people to stop telling her what a great job she's doing. "Good job" Good job!" she mimics. "It's like I'm in second grade and just got all my spelling words right."

And then she gets serious. "There are days when I wish my husband would just try harder. Sometimes it's like I'm the only one vested in his care. Why can't he take the meds like the doctor tells him to? Why is every doctor 'an idiot'?"

Yep — sometimes our patients don't put their own oars in the water and we are out there paddling alone — paddling alone for them. Invariably, we think, "If he doesn't care, why should I?" The front door is all that stands between us and freedom and don't think we don't eye it.

Also, please don't suggest that we need therapy to learn how to cope better. We aren't what's wrong and in need of fixing. What's wrong is that even though family caregivers save the country $500 billion a year by providing our services for free, nobody is out there trying to make our lives a little easier. Where are the tax credits, the expenses reimbursement, the paid family leave so that while I'm spending the night not sleeping in a chair next to his hospital bed I don't have to worry about going to work the next day?

But instead of solid counsel, all we get is your view of how you think we should be feeling.

Sadly, caregiver-shaming has forced some of us to go underground. There are secret groups on Facebook where caregivers meet during the insomniac hours to share and vent what we feel freely. We even have "Throat Punch Thursdays" — where we rage on the doctors who don't call us back, the pharmacies that can't figure out how to submit a bill to insurance, the morass that is Medicare and Medicaid and VA benefits that no one understands. And yes, sometimes we throat punch our patients. "I just wanted to go to the supermarket alone and walk up and down every aisle — alone. But he wanted to come along. Dammit." Sometimes, we could use a little care ourselves and we find it best among strangers who don't shame us for being open with our feelings.

In the judgment-free zone of Facebook — bet you didn't know such a thing existed — we get to say things like: "We don't feel honored. We don't feel lucky. We can't even love the same." Roll those words around your tongue like a fine wine and then let me know how you think we should feel.

What is Punding?

You may have not heard of the term "punding." The behavior itself is as uncommon as the term. Punding is a compulsive need to carry out a repetitive motor behavior such as sorting materials that you are no longer using, counting small objects, lining them up and then counting them again, or taking everything out of a drawer, examining it, and then doing it all over again. There is no apparent or gainful purpose associated with punding activities.

Punding has been described as "a stereotypical motor behavior denoted by intense fascination with repetitive, excessive and non-goal oriented handling, and examining of objects." It is generally precipitated by drug use and alleviated by a reduction or change in medications.

What's the link between punding & Parkinson's?

Parkinson's disease (PD) is a progressive neurodegenerative condition where there is damage to the dopamine-producing nerve cells in the substantia nigra portion of the brain. Activities such as counting pebbles, cars, and ceiling tiles are examples of impulsive and compulsive behaviors (ICBs), which characterize punding.

Punding is not obsessive-compulsive disorder (OCD). OCD is characterized by more compulsive, rather than impulsive, behaviors. OCD is a cycle of unwanted, disruptive behaviors. Obsessions are urges, intrusive thoughts, or images that can trigger intense and distressing feelings. Compulsions are behaviors to get rid of the obsessions and distress. Punding behaviors are different; they're idiosyncratic, generally linked to personal history.

The development of such impulsive and compulsive behaviors is believed to be complications of dopamine replacement therapy. Like so many Parkinson's traits, punding will not be experienced by everyone, but it can be disruptive and thus worth knowing about.

Why does it happen?

Punding is thought to be medication-induced in PD, especially at high dopamine replacement levels. As the condition progresses and dopamine loss becomes greater, people take larger doses of medication in order to alleviate motor symptoms.

In an effort to reduce off times, some people self administer a "rescue" dose. A compulsive overuse of rescue mediation beyond that needed to relieve of motor symptoms may result in punding.

Self-medication without medical supervision may result in the development of disabling behavioral tendencies. Remember, it is never a good idea to adjust (stop or increase) any medications without first talking to your doctor.

Punding behaviors are not unique to people with PD. They can affect habitual drug users of amphetamines and cocaine as well.

It affects each person differently

Just like PD affects each person differently, so does punding, for those who may experience it. Personal punding activities are idiosyncratic and may be linked to hobbies or past jobs; behaviors based on past experiences.[1] This can make it more difficult to recognize as punding behaviors develop.

Punding is not necessarily dangerous either to you or your family. However, due to its impulsive nature, there is the potential for harm. Most people find these repetitive behaviors embarrassing; others find they are a source of aggravation in their homes or offices because people get distracted and it can be disruptive to others. Punding tends to occur as the disease progresses and dopamine dysregulation increases. This can also make it a sensitive topic for discussion.

Long-term management of punding behaviors can become more difficult. Caregivers and family members to share information on punding behaviors with medical providers. They can help to formulate a treatment plan and foster coping strategies.

How is it treated?

Since there is no definitive cause or pathophysiology of punding in PD it has been difficult to develop therapeutic approaches to either diagnose early or prevent the developing behaviors.

Scientific studies have looked at a relationship of punding to levodopa usage – and how reducing the dose of antiparkinsonian drugs can reduce or eliminate the symptoms. It can be a delicate balance to regulate the dopamine replacement medications that control motor movements but bring on the systematic, repetitive activities.

Further research into ways to a balance the control of side effects and deterioration of motor symptoms is needed. Antidepressants and antipsychotics have both been used to treat punding, but such drugs may not be helpful to all since they are considered a contributing factor. DBS, deep brain stimulation, another therapy used for people with PD that generally results in the ability to reduce drug dosages and improve motor symptoms.

Punding is not driven by satisfaction, pleasure, or anxiety. Behavioral traits appear similar to those of OCD but more individualized and less distressing. Yet people who experience punding may find that the interference or disruption it causes can lead to anxiety or frustration.

What is Sundowning, what causes it and how does it impact the caregiver?

Posted: September 30, 2014 by Staff Writer

Category: Newsworthy Notes

Sundowning is basically a group of symptoms that may come with or without a disease. By itself, it is not a disease; however, it may affect people with Parkinson's, dementia, Alzheimer's, Lewy Body Variant and the like. Sundowning, by its very name, occurs at a specific time of day, generally starting in the late afternoon and lasting until bedtime. It is thought to be associated with impaired circadian rhythmicity, environmental and social factors, and impaired cognition.

Sundowning can be exhibited in any or all of the following examples: Agitation, anxiety, confusion, combativeness, ignoring directions, irritability, restlessness, and screaming or yelling and may even manifest in constant pacing and/or wandering. Some of these behaviors may not be specific to Sundowning and can be the manifestation of dementia, delirium, Parkinson's disease, and sleep disturbances. Other clinical features of Sundowning include mood swings, abnormally demanding attitude, suspiciousness, and visual and auditory hallucinations in the late afternoon and evening.

Research indicates that 20–45% of Alzheimer's patients will experience some sort of Sundowning symptoms.

The exact cause of Sundown syndrome is unknown. Several theories have been proposed to understand the clinical phenomenon of Sundowning. Studies that have attempted to explain etiology of Sundown syndrome can be divided into three major groups: physiological, psychological, and environmental. A change in the biologic clock caused by dementia is a likely reason.

A variety of treatment options have been found to be helpful to ameliorate the neuropsychiatric symptoms associated with this phenomenon to decrease the morbidity from this specific condition, improve patient's well-being, lessen caregiver burden, and delay institutionalization: bright light therapy, melatonin, acetylcholinesterase inhibitors, N-methyl-d-aspartate receptor antagonists, antipsychotics, and behavioral modifications.

Before considering any specific treatment for Sundown syndrome, it is reasonable to gather a careful history including a journal of the patient's daily timeline and activities as they pertain to the Sundowning, and have performed a thorough physical examination, and laboratory investigations in order to evaluate a patient for the Sundowning syndrome's possible connection to various medical conditions.

Determining What Triggers Your Loved One's Sundowning – As stated earlier, it is very helpful for caregivers to try to determine what may trigger Sundowning symptoms. There may be specific things that you might alter if you determine they may be triggering the behaviors. These alterations may prevent Sundowning from occurring or at least lessening its intensity.

Check medications for possible side effects.

Check with the physician to rule out pain or other developments that might be causing increased behaviors.

Have the lighting levels up which will reduce shadows and gloom.

Maintain an afternoon, evening and bedtime routine.

Play soothing music in the place of television or talk radio activities.

Stay physically active during the day; however, keep the daily activities from being overtiring or over stimulating.

Go outside into the sunshine during the day.

Keep naps short so as to keep them from being wide awake when they should be ready to go to sleep for the night.

Reduce caffeine.

Ensure the environment is calm and quiet, reduce noise, move to a quiet room.

Perhaps offer food and beverages prior to sunset.

Try to reduce their agitation by talking to them reassuringly about their concerns.

Redirect their behavior. Give them a task to refocus them and relieve boredom.

Keep nightlights on in areas that can be dark.

Ask the doctor if melatonin would help with sleep routine.

Unfortunately, most of the aggression is directed at the caregiver and the patient's behavior changes about the time the caregiver is tired from a long day and is hoping to begin to unwind. Even worse, the behavior changes and anxieties can last until bedtime, further worsening symptoms and escalating behaviors making it harder for the person with dementia to fall to sleep. The effect Sundowning has on a caregiver is not only difficult for the caregiver to deal with, it can be super stressful causing caregiver illness and burn out.

We continually encourage caregivers to care for themselves first by scheduling an hour, an afternoon, a day or longer of time for yourself. It is imperative to focus on your own needs, care for your own health and get support and respite every chance possible, especially when dealing with a person with dementia. If possible, schedule paid caregivers, friends, family members or others to take over some responsibilities so you can take time for yourself. Paid caregivers, friends, family members or others can help with household tasks or caregiving duties. In order to continue be a good caregiver it is critical to maintain your own well-being.

A caregiver can get wonderful emotional support from others who are in the same or similar situations. Join a caregiver group. Learn from and share with others their and your experiences. Others may have tips and techniques that could help you deal with your situation, while you may have tips and techniques that can help them. Mostly you will know that you are not alone.

Learn what is coming next in your loved one's disease process so you can be prepared. Ask for the Five Stages of Parkinson's and/or learn The Five Stages of Dementia which describe a patient's ability to perform in six different areas of cognition and functioning: orientation, memory, judgment, home and hobbies, personal care, and community.

The most effective way to deal with your loved one's Sundowning is to learn from each experience they have by keeping a journal of the symptoms; what may have triggered them? How was this day different from others? What physical signs did they show? How long did the episode last? What worked to calm them this time? By using what you've learned from each occurrence will make it easier to deal with the next one. Perhaps you will be able to lessen each episode or reduce the frequency of the experiences, which will make your job as a caregiver easier.

Disenfranchised Grief

Grief is defined as the emotional response to any type of loss. Loss of a loved one, loss of a relationship through divorce or illness, and change in life-style generated by a geographical or occupational move are all types of losses that create grief. Grief is characterized by feelings of sadness, hopelessness, depression, numbness, anger and guilt. The saying, "time heals all wounds" is somewhat true. In fact, as time goes by, the emotional responses associated with the grief tend to subside or lessen in intensity. On the other hand, disenfranchised grief hinders grief resolution causing the feelings associated with grief to persist for a very long time.

Disenfranchised grief is generally grief that is not usually openly acknowledged, socially accepted or publicly mourned. Examples of disenfranchised grief include loss of a pet, perinatal losses, elective abortions, loss of a body part, loss of a personality from dementia, and loss of a loved one who is not "blood related" (i.e. a boyfriend/girlfriend, extramarital lover, in-laws). Society disenfranchises grief and mourners by not recognizing one or more of the following: the relationship between the deceased and a survivor, the importance of the loss, or the need to be a griever. Society also attempts to regulate how, when, and how long people may grieve by placing terms such as complicated grief on those who seem to be grieving longer than they should. Grief and sadness make people uncomfortable. Therefore, we often try to make people feel better or we simply ignore or minimize their grief as something that they need to "get over." Establishing definitions of proper and improper mourning techniques is another way of excluding certain individuals, thereby disenfranchising them and their grief.

The goal in successful grief resolution is to reestablish emotional equilibrium.

The four characteristics for successful grief resolution include: accepting the reality of the loss, experiencing the pain of grief and all the emotions that follow, adjusting to the new environment without the person or situation and, finally, withdrawing emotional energy and reinvesting it in another relationship. When grief is considered acceptable there are rituals that surround and ease the pain of the bereaved, however this is usually not the case for those experiencing disenfranchised grief. There is often no extra bereavement leave from work or sympathy cards found to validate loss that society does not feel warrants sympathy. Dismissive and hurtful comments such as, "You're still young, you can have another baby," "Be glad you're still alive," or "It was only a dog!" demonstrate how unimportant these losses are to most people.

Disenfranchised grief can have multiple effects such as depression, emotional disturbances, withdrawal from society, psychosomatic illnesses and low self-esteem. Compared to those with more socially accepted types of grief, many of those dealing with disenfranchised grief tend to abuse substances and have difficulty in forming healthy relationships. Moreover, people with disenfranchised grief often have trouble in coping with subsequent losses.

When we withhold affirmation of the person's grief, memory of the relationship, the importance of the loss, or the needs of the griever do not simply go away. Rather, it causes bereaved individuals to cut off sources of support, forcing them to suppress their grief, and causing their problems to magnify. Therefore, people need to accept the fact that others may grieve and have intense emotional reactions to things which we may see as silly or unimportant. In accepting the fact that others may have these grief reactions, we can better prepare ourselves for the role of the supporter.

More information is available at these websites:

http://www.grief.net/
http://griefnet.org/
Written by: Veronica Thelen, L.L.M.F.T.

Reference: Thelen, V. (August 2007). Disenfranchised Grief. Mental Health Matters.

4(10). Gratiot Medical Center: An Affiliate of MidMichigan Health.

ParkyBoy

I communicate with and follow several other bloggers who are living with a person with Parkinson disease or have the disease themselves and write about it. This gentleman lives in England and has the disease. He gives his disease a name "ParkyBoy" and refers to the disease in the third person in his blog. This is a recent post of his and I thought I would pass it along to everyone. He is assessing his disease and life 3 years past initial diagnosis.

ParkyBoy writes from the perspective of having and processing life with the disease.

About Ropinirole (Requip) mentioned below - https://www.ncbi.nlm.nih.gov/books/NBK554532/
and Rasagiline – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2515917/

The state of ParkyBoy – diagnosis +3

SEPTEMBER 26, 2022~ PARKYBOY

I recently celebrated (nope… try ‘passed’) the third anniversary of being diagnosed with Parkinson’s. It feels a good time to reflect and share, as I did last year. I’m not just interested in ‘clinical’ issues, but the whole picture of the impact of Parkinson’s on my life. If this helps other people reflect on their situation, that’s great.

A lot has been happening. In many ways life is more difficult, but I’ve also been involved in plenty of positive things.

Parkinson’s symptoms

While I still ask myself “Is this a Parkinson’s thing?” when anything new crops up, I haven’t kept up to speed with recording what’s going on on ParkyBoy’s symptomometer, or my symptom of the month. I may come back and adapt these.

Back pain, which was an important symptom for months, has become less frequent and less severe. For example, I’m less likely to have pain while washing up, have less trouble turning over in bed and my left leg has magically shrunk back to the same length as my right, making it far less common that I need help putting on my left sock.
My left hand tremor continues to develop very nicely, often spreading right up my arm and shoulder. It remains tricky to carry out certain highly complex tasks, such as spreading butter on bread.
I frequently do the oh so characteristic Parkinson’s ‘pill-rolling’ motion while standing or walking.
Shoulder stiffness continues to be a problem, often while eating or going for a walk. I often feel as though my left shoulder is being gently, but consistently, pushed down, especially when I’m working.
Feeling cold became a really big thing for me (though difficult to imagine when the temperature here in Leeds was pushing 30 during the Summer!) I’m very worried about how this will affect me in the winter, when we’ll clearly all be chopping up and burning our furniture for fuel!
I’ve definitely spent more time being more anxious. This is often connected to work (see below). But if I had any doubt at all about it being a Parkinson’s thing, that was ended recently. I was on the RyanAir website (I know, I know… it can provoke anxiety in anyone!) when I reached the bit where they try to convince you that yes, you really do need to take five large pieces of hold baggage. In this case I actually started shaking, and realised it would be best if Kerry did the booking. My increased anxiety definitely collaborates with tremor and cold to make me feel very unpleasantly shaky. It’s my worst symptom at the moment
I also have a runny nose (but much less than I did), a general slowness which I find very frustrating, get foot and calf cramps, sometimes drool, and very occasionally have vivid dreams!
I forget more stuff than I used to, and I don’t process things so well. Is this a Parkinson’s thing? My personal jury is still out on that one!

I have a new symptom, which for now I'll call 'slo mo'. I can shift into it suddenly, when I say out loud, if I'm with Kerry, "I've just gone". It incorporates general slow movement with mental and physical shakiness, but also a feeling mentally of not being here, and sometimes feeling like I'm barely moving. When I'm in it, I really can't do much, or focus on much. I think the overall technical term is 'feeling completely crap'! I don't know whether 'slo mo' is a new, improved version of general slowness, or is a different thing altogether.

I've also developed a breathing problem. What is happening regularly is that I'll be sat working, then realise that I'm not breathing 'properly', almost as though I've forgotten to breathe. It just goes very shallow. It's not painful, but uncomfortable and concerning. Is this a Parkinson's thing?… I'm not sure. It's being investigated. My best guess is that it's a spin-off from anxiety.

And Kerry and I are both aware of a tremor having begun in my right hand. Disappointing, but much less sinister than the left.

Parkinson's medication

Having been told, at diagnosis, "We'll put you on medication", which I chose to defer, this has been a year+ of starting, changing and increasing medication, then increasing again.

I was prescribed Rasagiline, which my nurse soon told me she didn't have any faith in. I switched to dopamine agonist Ropinirole. It seemed to help initially then level off. I have just begun a second increase in dosage. I think it's now helping.

Health professionals

This is my opportunity to review how my own little Parkinson's solar system is developing.

Neurologist

I saw a Newrologist in August 2021. He said I would see him again, which sounded fine. When I mentioned to my nurse (in November) that I'd be seeing the Newrologist again soon, she told me he had now moved to the US! Last month – yes, August 2022! – I got a letter:

"…This is to let you know that your neurologist … has now left the neurology department and we are reviewing his follow up list. We will arrange to transfer your care to an alternative consultant and you will receive an appointment in due course".

I actually laughed out loud when I read it!

Last week I accepted a short notice cancellation with another Neurologist. He started by apologising to me for the "issues…with consistent follow-up…". I also appreciated him telling me, unsolicited, that his expertise was not Parkinson's, so if he were me, he would choose to see a Neurologist who did have such expertise. But after that I felt rushed. He judged me to be 'under-treated' (I think that's the third successive meeting I've heard that phrase) and prescribed another stepped increase in Ropinirole.

What stuck most with Kerry and I was when I asked what my expectations should be: "I want my patients to feel 'OK', 'alright'; not singing and dancing… which would mean I'd prescribed too much too soon." Thought-provoking. I may return to that one day.

He closed the meeting down. I came out OK…alright, definitely not singing and dancing.

Parkinson's Nurse

My 'regular' nurse was off work for a few months, which must have been really tough for her and her colleagues, not to mention people like me who want a bit of her time..

My last appointment with her, in November, was not a high point in my blossoming Parky career.

I saw a different nurse in July. She was very good, and I hope to see her again.

GP (also known as GD – the Good Doctor – in case you're not up to speed.)
I've seen my GD two or three times recently, about anxiety, breathing, Covid. And when my medication is increasing we work out together exactly how many truck loads of the stuff I'll need. She asks, she listens, she 'gets' me. If I don't exactly come out singing and dancing, I do come out singing her praises.

Neurophysiotherapist

In Autumn 2021 I was finally offered a Zoom version of the physio programme, PD Active, that I'd started before the pandemic. It was good, involving a mixture of physical effort, and multi-tasking.

Speech and Language Therapist

I'd almost forgotten that I was on the waiting list, but in May this year I did a series of speech and language sessions – on Zoom, of course. I got a lot from it, including understanding that if trying to be louder, people with Parkinson's are likely to believe they are shouting. While I have stopped doing the exercises, I constantly remind myself to think LOUD, in everyday conversation, when playing sport, and while singing.

Occupational Health Advisor

I've just spoken with an Occupational Health Advisor. The intention was to explore what I and/or the organization I work for can do to help me keep working effectively for as long as possible, and to plan for how to cope as this thing I've got develops.

I didn't know what to expect and was a bit nervous, but she listened, and told me that her father had Parkinson's, so there was a lot I didn't have to explain. She's made several recommendations, the most interesting being a 'stress assessment'. My organisation is a good, supportive employer, so already does many positive things.

Exercise

I've continued to be very active in the kind of 'exercise' that I have always enjoyed: put a ball/shuttlecock in front of me and I'll chase/kick/hit/catch it. I'm less keen on the other 'Exercise'.

Table tennis

Table tennis has been one of the best things for me in the last year. I played in the inaugural Parkinson's UK Championship last August (and won a medal!); I made some friends; in the Spring I actually went ahead with getting my backyard sorted and bought an outdoor table; I took part in the second UK Championship in Glasgow last month (no medal, but a quarter final), and I organised my own little table tennis tournament for friends. In October Kerry and I are going to Pula, in Croatia, where I will take part in the PingPongParkinson World Championship!

While I enjoy these tournaments, It's all a bit of a luxury. I'm taking baby steps towards setting up a Leeds group, to help more people benefit. I hope I'll have the energy to get there.

Walking football

I really enjoyed kicking a ball again, when I met the guys from Pennine Parkies in January, and joined the club. It's been tricky for everyone to play regularly at a good venue. But we may now have cracked that, as we've started playing every two weeks at a great community venue in Bradford. Perhaps the most unexpected thing I've done in the last year was to take part in a trial – not in a court, but on a pitch…for England! I did OK on a long day trip to Solihull, but didn't make it into the world's first PD Walking Football team. I'm delighted that four of my Pennine Parkies team-mates did. They await their international debuts. There was much talk of boyhood dreams!

Badminton

After a long, Covid-induced break, I've been back playing enjoyable, sociable doubles with friends, for months. The skill gap between me and the others has got bigger, as I've slowed, and my vision has got worse.

ParkyBoy in the Parkinson's community

If you are my reader (thank you!) you may have noticed that after publishing pretty much two blogs a month for about 18 months, I stalled completely this spring. This is just my second since March (and it's taken me forever!). I've also fallen off Twitter in the same period, and haven't been keeping up to date with my ParkEfriends' work, such as Parky Tracks, Who stole my dopamine and Twitchy Woman. (I haven't forgotten you!) This was not a decision. I haven't run out of things to say. I think it's a result of life, including work, being tougher, and having less head space. Perhaps I just needed a break?

On the other hand, through sport, I have met more actual people. In table tennis in particular I am part of building a community. Who knows where that will go after the world championship next month!

Friends and family

I've seen friends far more than in the previous, more covidy year, though things haven't fully recovered. My favourite local restaurants have all closed since February! My local cinema still hasn't reopened – it's going through a major development and it will be fantastic when finished.

I managed to get my grandson Félix hooked up to my local cricket club and, wonder of wonders, he's loved playing. One of my highlights of the year was spending the day watching the great Jonny Bairstow score a fantastic century for England, then walking through the woods to arrive just on time, at a smaller, quieter, ground, to see Félix come out to bat! It's also allowed me to spend far more time with him and his mum.

I've seen my sister, my dad, and my aunt and uncle, but none as much as I would have liked. Everything is more of an effort than it used to be.

Travel

The confluence of PD and Covid sadly put paid to my and Kerry's intended big trip to Chile. I've been learning about managing PD through other trips.

Our holiday in Malta was the first such to be affected by Parkinson's. Kerry also went on a walking holiday in Italy. She wanted to do something more demanding, which I didn't feel I could do. I encouraged her to go without me, and when she got back she agreed that I would have found it difficult. But it was a sad moment for both of us.

We intended to go to Oxford for a long weekend, to see my aunt and my visiting Czech friends. At the last minute Kerry had a Covid scare and rightly chose not to go. It was the week where the temperature broked UK records. I was full of anxiety. I went, and was pleased to be there, but it really made me question my ability to travel on my own. It's also informing how Kerry and I manage my possible anxiety on the epic overland trip to Croatia that we're embarking on soon.

Music

I'm still playing ukulele (and pretending to sing) with Music from the Attic. Sometimes I have to push myself to get there. I almost always enjoy it, but my anxiety gets right in the way of me just chatting with fellow members. We had a lovely day at Kirkstall Festival, playing two sets to decent crowds.

Work

I still work – three days a week – doing communications for a local charity that supports the wellbeing and independence of older people. I (all of us) am delighted to have had another year's extension, but I do three hours a week less than I did. In some ways this helps me, but it's just tipped the balance in terms of being able to get my work done. That's been difficult at the same time as trying to cope with PD related anxiety. I feel less confident, less skilled and less connected, but still happy to be working in something worthwhile, with lovely, supportive colleagues.

Covid-19

Covid finally caught up with me (and Kerry) in April. It was low-key, and in a way, partly a strange relief to get it. But my caution through the pandemic felt fully justified when my PD symptoms gathered new momentum. I'm now pretty clear that there's a direct connection.

How has your last year been?

Websites and other Info.

When you find yourself being a care partner to a Parkinson's disease patient or any other patient of a chronic progressive disease, you will find yourself reading anything and every thing about the malady. These are a tiny sample of the websites, blogs and other information.

No opinion is implied by my including them here.

https://parkinsonsdisease.net/clinical/punding-symptom-treatment

https://www.apdaparkinson.org/

https://www.parkinsonsresource.org/news/articles/what-is-sundowning-what-causes-it-and-how-does-it-impact-the-caregiver/

https://seniorsafetyadvice.com/about-us-2/

Blogger: Cheryl Hughes – Care for Parkinson's – https://parkinsonscaregivernet.wordpress.com/

Blogger: Paul J. Weisgerber – Adjunct Wizard – https://adjunctwizard.wordpress.com

Blogger: Rob -- Parkyboy - https://parkyboy.wordpress.com/

Michael J. Fox Foundation - https://www.michaeljfox.org/

Davis Phinney Foundation - https://davisphinneyfoundation.org/

LSVT Big - https://www.lsvtglobal.com/LSVTBIG

Parkinson Community Fitness - https://parkinsoncommunityfitness.org/