



**Paul Don Erdman**

January 18, 1957 - October 21, 2015

58 Years

# Peter's Journal of Paul's Journey

Narrative taken from notes and dictation made each day after visitation  
with context provided by Kathy

# PETER'S JOURNAL OF PAUL'S JOURNEY

SEPT 12 (SATURDAY)

TRINITY LUTHERAN CHURCH & CANADIAN HONKER, ROCHESTER

*Paul was best man for his son's wedding. It is believed that the tumor was starting around this time.*

SEPT 21 (MONDAY)

*Paul was working on a job site when he started to have trouble doing calculations. John (Paul's boss) arrived onsite and sent Paul home.*

SEPT 22-25 (TUESDAY-FRIDAY)

*John had Paul work the remainder of the week at Courtney's (a wealthy individual who would often hire Paul for weeks at a time to do electrical work on her estate). He thought it would be less stressful for him to work there since it was familiar territory.*

I remember Paul telling me that from time-to-time Courtney would embark on a project that could be characterized as lavishly eccentric that often pushed the limits of her contractors. She spent ghastly amounts of money on things that she would never use, and yet she was quick to fire contractors who were too eager for her money. Paul enjoyed the work and interacting with her. He said it was just a matter of taking her at face value and being genuine in return. Paul was the only electrician that she consistently invited back for more work.

Paul put into practice what is often merely preached.

He was quick to admonish the inevitable criticism toward Courtney when he would tell stories about his latest "electrician adventures" with friends and family. He would say "Who are we to judge?" and then continue with his odd but true story. Paul's gentle yet brazen integrity let him share entertaining stories rooted in this woman's economic eccentricities, while at the same time not resorting to degrading her character.

SEPT 26-27 (SATURDAY-SUNDAY)

*Paul spent the weekend at home with no incidents.*

SEPT 28 (MONDAY)

*Paul said that he was not going to work because his stomach hurt. This is Paul's catch-all symptom that Kathy knows can sometimes just be "a case of the Monday's".*

*Kathy told him to either get up or go to the Doctor.*

*He got up and went to work.*

SEPT 29 (TUESDAY)

*Paul went to work.*

SEPT 30 (WEDNESDAY)

*Paul and Kathy had an appointment with their family physician regarding symptoms of memory loss and trouble with balance. Symptoms seem to indicate stress and he was about to be sent home with meds. Unsatisfied, Kathy asked "what about his balance?". After the Doctor saw Paul walk a few steps he immediately ordered a brain scan.*

#### OCT 1 (THURSDAY)

*Paul had a CT scan which picked up a large brain tumor. Doctor called Kathy who in turn called Mike. That evening Mike and Kathy told Paul that he had a brain tumor. Paul was not comprehending what they told him and was rather cavalier in conversation. Paul asked Kathy why she was crying. She said it is because you have a brain tumor. Paul replied, "these things happen...what are ya gonna do?" and forgot what just happened within a few minutes.*

#### OCT 2 (FRIDAY)

*An MRI showed the tumor was in the center of the brain and in both hemispheres.*

#### OCT 5 (MONDAY) 6<sup>TH</sup> FLOOR, MARY BRIGH BLDG, ST. MARY'S HOSPITAL, MAYO CLINIC

*Paul checks into St. Mary's Hospital at 9 am for a brain biopsy. The surgery was performed by world-renowned neurosurgeon Dr. Lanzino at 5:15 pm and lasted just one hour. He chose the more invasive open biopsy procedure for direct observation. Family visited him shortly after surgery, but Paul was unresponsive.*

I arrived at about 7:30 pm expecting lots of activity and a few comments about being the last one to arrive. As I wandered through hallways and waiting rooms I found more and more of nobody until I reached Paul's room. There framed behind a window was a propped-up unresponsive and alone Paul with a gauze bandage on the top of his skull. It was a rather somber moment as it became apparent that I was too late. But as I was about to discover I was there at just the right time.

A nurse took me into Paul's room and asked him if he knew who I am. Paul's eyes got very large and he reached out his right hand toward me. He could not talk and kept clawing at his throat. He grasped my hand and tapped it with his other hand several times as he stared directly into my eyes. The nurse asked if he could wiggle his toes - which he did several times. She asked again if he knew who I am. Paul answered, "my Brother, Peter". She then asked Paul where he is and what the date is. He said, "Methodist Hospital" (pretty close!) but he got the date wrong. He was getting noticeably agitated and started to pull at the stitches on the top of his head. I walked out with the nurse to ask a few questions before leaving. She encouraged me to continue visiting. Paul sat up and had a conversation with me...it was rather fragmented and repetitive as he was clearly struggling with comprehending what was going on.

#### OCT 6 (TUESDAY)

*Dr. Lanzino reported the results of the biopsy at about 5 pm - a week early - stating that the diagnosis of Glioblastoma is the third worst case he has seen in his career.*

Dad called me to break the news of Paul's prognosis.

#### OCT 7 (WEDNESDAY)

#### OCT 8 (THURSDAY)

*Pam starts a Caring Bridge site so friends and family can be informed on a daily basis.*

OCT 9 (FRIDAY)

6<sup>TH</sup> FLOOR, MARY BRIGH BLDG, ST. MARY'S HOSPITAL, MAYO CLINIC

I arrived late in the afternoon to visit Paul for the first time since his diagnosis.

It took me a little while to acclimate to Paul's state. It seems like he is merely in a daze and was choosing to not engage in conversation. Sure, I understood when Dad said that the Doctors told him that Paul was functioning at the level of a 3-year child. But I certainly did not feel 50 years older than my older brother. I kept my guard up expecting a big "just kidding" the second I would say something silly. For the next few hours reality set in as I observed him interacting with family and friends.

Dad shared with me yesterday's experience of Paul eating ice cream. Everyone had some good laughs as Paul thoroughly amused himself eating ice cream with his spoon upside down. The thing is that I didn't see Paul laughing along with us at the retelling of the story. This seemed very odd to me. Apparently, he isn't "just kidding" and really is oblivious to what is going on around him. Hum.

Later, it was time for dinner. Dad said that Paul has been quite amused by trying to land the contents of salt packets somewhere near his food. I noticed that he was successful by landing the better part of two packets directly on his chicken strips. That is a lot of salt! He started to eat rather fast and began choking. When he was told to slow down he began shoveling them into his mouth faster making a bit of a game of it.

It seemed to me that he just needed to be distracted by something more interesting than heavily salted chicken strips. I went to the car and brought in a few things including a folder of information about the new furnace I was installing at home. The electrical diagrams did the trick. He looked up at me like I had just given him "Something Old, Something New, Something Borrowed, Something Blue." and then went right to devouring each page. Not only were the chicken strips a distant memory, so was everything else in the room as he delved into things of familiarity with child-like wonder.

Then suddenly his attention shifted to the tethered nurse call pendant laying on his bed. The more he couldn't quite reach it, the more determined he became in getting his hands on it. He wanted to push the buttons! He said that he needed to "approve for the nurse" and "authorize this for the nurse."

Dad picked up on this right away and told him "no that is not something that you are to be doing". They went back and forth playing tug-a-war with the call pendant with Paul laughing as he eventually got ahold of it and pushed it. At that point Dad unplugged the pennant and asked me to reset the call switch. The game had gone too far, and Dad needed to gain control over this situation before, heaven forbid, the nurse would show up.

Paul did not like the pennant being unplugged and was become animated enough to begin standing up while strapped to a large wooden recliner. He was taking the matter into his own hands by sheer will power. Naturally Dad had a strong reaction to this and got him to settle back into the chair. Within a few minutes it was obvious that Paul had an accident, so ironically, we called for a nurse. Paul was now the hub of conversation with Dad, two nurses, and several visitors all being shuffled to the hallway. Dad was heading back into the room to retrieve my Mom who was still in the room napping. I eventually convinced him to stay out in the hall and let the nurses do what they need to do. In my opinion it was better to have Mom off in the corner instead of having one's Dad barge back into what was probably at that point a rather embarrassing situation for my Brother.

The consensus was that this was just a playful game of tug-a-war; after all his laughter and affect indicated just that. Nobody seemed to make any connection between the scrimmage and the accident. Hum.

As the day wound down my Dad and Sister asked about my plans for the upcoming days. They were making plans themselves and given my spotty attendance at family events over the past few years it's understandable that they wanted firm commitments from me before I slipped away.

I simply said that my one and only priority is Paul. Since we don't know what this may entail until the days to come, it is essential to make plans that don't constrain my ability to adapt my schedule as events unfold. For example: I am all for agreeing to meet at a certain time and place, but when these plans are extended by figuring out who should ride with whom then I have a problem with it. If someone genuinely needs a ride then I am there for them, but if we are just trying to save a trip or two then this doesn't work for me. I don't want anybody to depend on me for a ride when that ride might restrict where and when I can be there for Paul.

#### OCT 9 (FRIDAY EVENING)

Friday night was an example of needing to make trade-offs to do what it right. It was Mom's birthday and we were all going to Texas Roadhouse for dinner.

The restaurant was packed, very noisy, and had a very long waiting line. It just didn't make sense to me. The whole point of attending would be to talk with Mom - which would be impossible. As much as I wanted to celebrate Mom's birthday and assimilate with family - I choose to skip dinner and go back to the hospital. I just wasn't buying this notion of him functioning as a 3-year old child. I had to find out what was going on with Paul.

After my return visit to see him there was zero doubt in my mind. He was reaching out to tell me something. I needed to step up to the plate and figure this out. I am sure that I got some rolled eyes over the next couple of days as I spent more time figuring this out than visiting Paul. For the last ten days of his life I took a very different direction in how and when I visited him. It was quite noticeable that my family didn't get why I was doing what I was doing. But I am OK with that. I did what I had to do.

And it was the right thing to do. For Paul. For family. For me.

#### OCT 9 (LATE FRIDAY NIGHT)

#### DRIVE HOME TO EAGAN

On the way, home I reflected on what happened.

**Why didn't Paul laugh when Dad was telling the story to me when clearly, he laughed a great deal when it happened a day earlier?**

Because it wasn't funny. It would be totally in character for Paul to laugh at himself such as what undoubtedly happened yesterday. He loves laughing with people but does not find any humor in laughing at people. Including himself. I don't think that he liked the retelling of yesterday's hijinks since he probably didn't remember it and thought that people were laughing at him.

Paul likes to live and let live - going with the flow. He can be playful and loves to laugh, but he would never do either at someone's expense. So, his humor tended to be rather dry and semantically oriented. (How do you catch a unique rabbit? You 'neek up on him!) Droll? Very. Mean spirited? Not a chance.

**What was really going on with the nurse call pendant?**

To Dad this was a Father-Son scrimmage where Paul was once again a 3-year-old child. Dad saw Paul smile, so he played along, but then took on the authoritarian caretaker role. After disarming the call pennant, he insisted that Paul tell him what it is that he needed. Paul would have nothing to do with that and wanted the button back.

Paul's communication was crystal clear. His word choice was not always correct. His affect was not very precise with only a few expressions: laugh, smile, ponder, discontent. Taking him strictly at face value strips him of his humanity. By putting his words, affect, and expressions into context of knowing him for 50+ years was a jaw dropping experience for me. This is the Paul we all know, and he is communicating in no uncertain terms!

Paul had an upset stomach and urgently needed to go the bathroom before there was going to be "explosive" consequences with a room full of visitors!

To Paul this started as a little scrimmage with Dad, but rapidly escalated when he was being treated as a child. He was taking charge of the situation!

He urgently needed the help of a nurse, but certainly was not about to give this much detail to his own Dad! He wanted some discretion around friends and family with the dignity of an adult, not a 3-year-old telling Dad of such matters.

This is classic Paul behavior when interacting with Dad. Easy going and even a bit playful in matters of disagreement - until Dad crosses the line separating Paul the child - and Paul the man, husband and father. There was never a battle of wills or an exchange of harsh words - Paul would just give Dad "a good looking at" that said in no uncertain terms to not go there. Period. Now let's go watch a movie or go fishing.

The Paul I know is alive and well despite that his ability to communicate was rapidly deteriorating such that he outwardly appeared to be a young child. I need to change the way I am approaching my visits with him. I can't treat him like a child when I know that the same Paul I have always known is in there. I also can't let his lack of memory and comprehension be reason to not include him in any conversation in his room. For this to happen I need a crash course in how to communicate with someone who has a brain tumor. Nothing touchy-feely here. I just need to know the facts and the practicalities of how his brain is now processing information.

OCT 10 (SATURDAY) 6<sup>TH</sup> FLOOR, MARY BRIGH BLDG, ST. MARY'S HOSPITAL, MAYO CLINIC

During the overnight I packed 7 suitcases with everything I could find that he might find familiar and comforting. Pictures, newspaper clippings, technical manuals, record albums, stereo equipment, catalogs - even one of those hang on the car window speakers that he got for us from a drive-in theater when it closed years ago. I thought something familiar would help ease his mind.

I was in the big chair next to Paul's bed when Pam and Kathy were having some casual conversation about his upcoming healthcare needs. Paul was clearly becoming restless in the crossfire of opinion as everyone in the room was weighing in their opinion - except him. He hates conversations like these and began showing his discomfort by tugging at some gauze wrapped around his lower right arm. Dad said that he can't be doing that. Kathy said yes, he can - they left it on him when they took out his IV and wasn't needed anymore. Paul got it unwrapped and cast it aside. As the conversation intensified Paul started to tug at his hospital bracelets - again on his right arm which was closest to me. Dad told him to stop doing that.

Not being a party in the conversation I couldn't help but notice that the room was very boring at a precognitive level. There was nothing intriguing for him to relate to. Sure, there were lots of newspapers, cell phones, greeting cards, and medical devices - but with the single exception of the Shopko advertisement, it was all cerebral stuff. He

adored Shopko's graphic laden pages of familiar household objects earlier in the day...but apparently, he would have to wait until next Sunday to get his hands on another issue. He must have felt quite alone with a bewildering array of conversations taking place all around him, but without him.

By now he was tugging his hospital bands with gusto the more Dad told him that he can't be doing that. They went back and forth in a little battle of wills, but he was not able to rip off the bracelets like the gauze. He then started to pick at the edge of one bracelet such that he was peeling it apart and beginning to remove it. Dad would have nothing of this and told him to stop. Paul playfully picked at the loosened edge as he got a great big smirk on his face. He looked at Dad, then at me, again at Dad, and finally when Dad looked away Paul looked right into my eyes and yanked the bracelet completely off and handed it to me. I took the bracelet to the nurse's station - no big deal - they made him a new one and put in on his other arm.

The tug-a-war seemed like good natured play - good to see him being a little feisty.

He immediately tried to pull the new bracelet off.

Time for me to go to the car and bring some things in to occupy his attention. I dug through my luggage and selected a few things that seemed likely to garner his attention.

I showed him pictures of himself in High School plays, pictures of a Space Needle ride (just like at the State Fair) that has been for sale in Wisconsin that we went to see in the early 1980's, and a big can of tuna (really big!) – which he burst out in laughter and smiles the second he saw it.

I then gave him a packet of about 20 pages of rare historical pictures depicting Royal American Shows – the midway of all midways at the Minnesota State fair during the years we grew up. The size of this midway was only eclipsed by the seediness of it. Too big for mere trucks, this show took over 100 custom railroad cars using tracks leading into the fairgrounds itself. We were both fascinated by it, but the reality is that it was made up of sleazy people, degrading freak shows, and hustlers conning people out of their money. This was no place for naïve kids from Rochester, however, Dad did allow us one walk through. In the daytime. Together. Staying in the middle of the walkways. Keep walking. Don't stop. Most importantly, don't make eye contact with the carneys.

When he came to the pictures of the freak shows, he flipped through them as fast he could, as if rolling his eyes at me as to why I printed those sleazy pictures. But he kept turning back to one page. Each time he examined the picture very carefully and then glanced up at me and then quickly turned the page. He was probably a little perturbed that I put a picture in there of the freak show that we went to on the sly after being sworn to secrecy so many years ago.

So, Paul must really be in there!

(In the interest of full disclosure my Sister, Pam, years latter 'dragged' me to the freak show where a lady turned into a terrifying gorilla right before our eyes.)

Later it seemed that Paul was both bored and overwhelmed with a full day of stimulation. So, I went to my arsenal of stuff and whipped out what I knew would be a home run – an installation manual for central air conditioning! He devoured it. He was completely absorbed by the diagrams, charts, schematics and parts lists. Clearly, he was in comfortable and familiar territory as he turned the pages and ran his finger across tabular information. Then something quite remarkable happened. I put the original installation sheet that he used to install my home air conditioning way back in 1985. He went right for that page - pointing at his handwritten notes.

He looked right at me with eyes that said he was proud of me. I brought him something that we both found more interesting than the one topic he hates most – medical stuff. It was a bonding moment going back to the days when we did Saturday projects together. This could only be topped by Kathy periodically stopping the lawn mower so that she could fetch up some icy-cold lemonade to top off Paul's Bug's Bunny glass as he cranked up the air conditioning to fend off the summer heat.

#### OCT 10 (SATURDAY NIGHT)

#### SLEEP OVER IN THE HOSPITAL

Before settling in for the evening I asked Paul if it would be OK for me to setup shop next to his bed. He nodded and continued being in a daze from a very busy day. I dimmed the lights and repositioned furniture so that I could work at a small table without being intrusive. I felt pressured to to break the awkward silence, but I knew that would not be a good thing to do so I immersed myself in some work and kept my mouth shut.

(It is quite the dilemma for brothers to share living quarters. On one hand it is nice to not be alone, but on the other hand it is nice to be alone! The universal solution is to build a barricade between us. It could be a wall of furniture in a shared bedroom, an array of cereal boxes at the breakfast table, or even a virtual wall formed by one's older brother after he has convinced his friends that he has no brother.)

After a while it started to seem less peaceful and more like a standoff. I was doing my best to be complacent and quiet while he remained sitting up in bed with glazed over eyes staring at the TV. I had to retreat so I went to the vending machines for a snack. When I returned to his room he was all tucked in sleeping soundly. I think he was indeed lonely and sought out things that are familiar and comforting to him. There was no doubt in my mind that I played that role during the day and evening, but clearly at night this was not a familiar thing for either one of us. For many (many!) years now we have each established our own separate living space - gone are the days of shacking up in the same room. More proof that Paul is still the Paul I know – an adult. Sure, it was difficult to see him alone and scared, but having him stare at the TV all night while I over stay my welcome is not going to help either one of us. So, I packed up and walked out.

#### OCT 10 (LATE SATURDAY NIGHT)

#### DRIVE HOME TO EAGAN

I gave this incident along with yesterday's incident a great deal of thought on the drive home and through most of the night.

##### **Why did he remove the gauze from his arm?**

Simple. He was bored and needed something to do. Dad just didn't know that Paul was told earlier that he could take it off himself. Nothing more. Nothing less.

##### **What was really going on with the hospital bracelet on his wrists?**

We all assumed he was just being playful tugging at the bracelet, but then why did he intentionally rip it off when he was told not to do that? This seemed out of character for Paul.

Paul is not someone who disrespects his Dad. Disagrees? Oh yes. Argues? To a limited degree. Disrespects? No.

This was no game. It seemed like a "in your face" - an act of defiance. He seemed to want more than just getting the bracelet off- he was doing so in a very deliberate manner making sure that both Dad and I saw him remove it.

##### **Why did he choose the purple bracelet?**

Of the several bracelets around his wrists why did he choose the *Do Not Resuscitate* bracelet during the discussion across his bed about transferring him to a Hospice?

If he didn't agree with the decision to not treat his cancer it seems that this would be an obvious way to protest as he is about to be carted away to die.

What if we are all moving him down the path of imminent death while he is wanting to fight this scourge and live?

Maybe he wanted just to get out of the hospital.

Maybe he just wanted us to stop talking medical stuff.

Or, -- maybe he just liked the bright purple color.

So, we are either killing him or he just likes playing with colorful toys. Seems simple enough – there can only be one answer.

This bone chilling revelation presents a truly profound dilemma for me.

In no way shape or form do I want to disrespect the decisions that have already been made. But make no mistake about it, if Paul is trying to say something that is not getting heard then I will take *whatever* measures are necessary to ensure that he is heard. While it would be nice to broach this subject with family, it simply can't be done without causing a great deal of anguish for *everyone* involved. There simply is not enough time to have a considerate and diplomatic series of conversations with each family member that would be sufficiently revealing to ensure that my comments don't go too far or not far enough in advocating for my Brother.

I need to first understand the physiology of communicating with Paul so that I can then have a meaningful talk with a professional about this so that I can then determine my course of action with family.

OCT 11 (SUNDAY)

6<sup>TH</sup> FLOOR, MARY BRIGH BLDG, ST. MARY'S HOSPITAL, MAYO CLINIC

Pastor Schwartz of Trinity Lutheran Church arrived to celebrate communion with Paul and those who wished to participate. As he prepared the elements my Dad interjected by asking if Paul was aware of what was about to happen so to be spiritually prepared to partake in communion.

Pastor Schwartz responded in a most brilliant way by not offering analysis or opinion. Instead he turned to Paul and asked a series of questions - clearly and distinctly - starting with: "Are you a sinner?" Paul responded to each question with a simple nod of his head. Pastor turned to Dad and asked rhetorically if that satisfies him and then immediately proceeded with the Words of Institution.

I had a few tears as the gravity of what may be Paul's last communion set in. The Pastors ritualistic words were reminiscent of my growing up years and quickly put perspective on the here and now. Paul was looking directly at Pastor Schwartz and seemed transfixed and a bit choked up. I lost it. I cried profusely through the whole thing. With no Kleenex within reach it just got worse. But I didn't care. As communion wound up I came to the realization that these were not tears of grief or of sadness. I was not sad about Paul for one minute. Truth be told – I was green with envy. There was no doubt in my mind that he was at a level beyond the Pastors words. It is as if he had one foot already in the hereafter and in just a few short days he gets to rejoin the almighty. Lucky dog.

As more visitors arrived, I asked Dad to step out into the hallway to chat for a few minutes. I told him that I have a dilemma that came up with Paul yesterday and that I need to talk to someone about it very urgently. I didn't give

him all the details, just enough so that he could find an appropriate medical person to talk to. We had an understanding that this needed to remain strictly between the two of us until I figure out what is going on. Then, and only then, could I make an informed decision on what, if anything, to share with others about my experience with Paul. He was not so much focused on what I was saying as that I was getting what I needed to put my mind at ease. We talked for well over an hour as we watched a small army of visitor's stream in and out of Paul's room.

I went outside for some fresh air figuring that Dad would set something up with a staff MD in the next day or two. When I came back Dad was talking to a staff nurse and said that he would be willing to talk with me.

I gave the nurse a brief overview of my questions thinking that he would line me up with an appropriate Doctor. (Somebody of the caliber of Dr. Lanzino – someone who really knows his stuff and can cut to the chase since Paul is heading to the Hospice in a day or two.) Dad encouraged me to explain everything so that I get my questions answered. Quite frankly I was getting a little perturbed because I didn't need a counselling session to feel better – I needed cold, hard facts.

When the nurse started to give detailed answers to my questions, it became very clear that he was the expert in this area. Clearly, he had the education to explain the physiology, but more importantly he had the experience of communicating with patients like Paul – something that an MD probably wouldn't have much of. We talked about this notion of Paul being a 3-year old – what a neurosurgeon told Dad. The nurse gave a far superior explanation by talking about what Paul is likely experiencing and put into perspective the rather crude 3-year old analogy that surgeons tend to use. So, as it turned out I got far better advice by not talking to the expert that I was seeking. Or, as Dad put it after making apologies for his language and tears - "You are one damn good nurse."

So, what did I learn?

People communicate through the following sequential steps:

1. Intake processing (sight, sound, touch, etc.)
2. Comprehending meaning
3. Forming a response
4. Physiologically devising the means to communicate the response (speaking, gesturing, writing, etc.)

People with brain tumors vary widely depending on the impacted regions of the brain, but it is not uncommon for these steps to take over a half hour to process. This is particularly the case with the last step of figuring out how to physically communicate a conceptual response through speech or gestures. This has nothing to do with intelligence or maturity – he is still the same person he always has been.

Paul likely has Wernicke's Aphasia which can occur when there is damage to the frontal lobe of the brain. This area is responsible for language production. The patient is expressive but in a non-fluent and protracted manner. The patient may not be aware that their speech is not as they intend it to be, however they will have awareness that they are having communication difficulties. Examples:

- They may use one or two words rather than full sentences
- Not be able to use the word they would like to say
- Get words muddled up like "wife" and "mother"
- Get words inverted like 'yes' when they mean 'no'
- Can describe an object but not name it
- Vocabulary may be limited to emotion words or swear words

The critical takeaway is that these patients are still intelligent, know what they want to say, and still have some decision-making capability. Don't pretend to understand what the patient said or complete their sentences – this will greatly increase stress since they probably won't be able to communicate that they know you are patronizing them. Not nice! Use short, simple sentences covering one topic that can be answered yes or no. Open ended questions like asking what they want for lunch or how they are feeling today are going to be virtually impossible to answer without someone eventually filling in words for them. Not only is this frustrating but after time resentment will start to build. Radio, television, children, and people moving about can be major distractions for the patient struggling with sensory overload.

I got a little worked up from this since it confirmed what I have been picking up on. Paul is being bombarded by dozens of people in his room, multiple simultaneous conversations taking place, the TV playing, nephews singing songs, Dad asking him open ended questions on what he wants...whew! If each of these is taking several minutes for Paul to process, he must be exhausted and very frustrated. This was so apparent when I gave him some papers to look at. He would examine them for several minutes and then stare at me. He would smile and point to the page which everybody in the room would acknowledge by saying something or asking him something. I got increasingly angry about this because he had something to say but kept getting interrupted. We all need to shut up for 5-10 minutes and just sit there attentively staring back at him until it is our turn to talk again. To me this means no cell phones, no side conversations, no people coming and going, no newspaper reading, no football game watching – just basic courtesy.

We then talked at length about my two primary concerns: Paul being bombarded by visitors, and what was the meaning of Paul ripping off his purple 'Do Not Resuscitate' arm bracelet?

The nurse agreed with my concerns about the large influx of people coming and going to Paul's room and said that he had the same concerns over the past few days. He said that it is his job to deal with this situation, so he would be taking it from here. He recommended that our conversation remain private so that the message would come directly from him as a professional. After considerable conversation it was clear that we were both on the same page: do what is best for Paul, and don't do anything potentially divisive with family.

He said that in his experience patients tend to gravitate toward bright colorful objects, so it could very well be just that simple. But then he had one stone-cold reality that cut me to the quick. Even if Paul intentionally ripped off the DNR bracelet to communicate that he didn't want a DNR order on him or even if he didn't want to go to a Hospice to die and wanted heroic attempts at treatment – it wouldn't change anything. Paul does not have the mental capacity to make this decision for himself. Not because he is a child or has severe short-term memory loss. Paul is still very much alive and in there – but he also has a very nasty brain tumor. It would be considered cruel and unjust to expect him to be put in the position to make decisions like this. He may be sad or angry or confused – but he needs to know that those that love and care about him will be making these decisions.

For as long as I am earth-bound I will never know what Paul was trying to communicate to me. Perhaps it was just a game and I completely misunderstood. I have no problem with that. No harm done if I keep my mouth shut. On the other hand, if he was putting out an SOS for me to intervene on his behalf, then this could haunt me for many years if I don't do something decisively right now.

Here is how I found peace.

Paul was desperately telling us that he is alive, viable, and very much a member of this family. He wanted to connect with family and friends at his level of functioning - *not as a child*. In short, his message was I am still here!

Treat me like your brother for I am still very much him. Communicate with me in a way that acknowledges that I have a brain tumor - a medical condition - but not in a way that makes me the brain tumor.

#### OCT 12 (MONDAY)

*Paul seems tired and mostly devoid of emotional expression as the steroids have run their course against the progression of the tumor. He remains pain-free, comfortable, and blissfully unaware of what is happening to him.*

#### OCT 13 (TUESDAY)

*Transferred from St. Mary's Hospital to Seasons Hospice*

#### OCT 14 (WEDNESDAY)

*Paul is not speaking at all. Even grandson Grayson didn't seem to evoke much of a response today. Paul is awake and looks around, seems to know people but that is becoming less certain. Still eating well. Does not make his needs known but will cooperate with having them taken care of.*

#### OCT 15 (THURSDAY)

*Paul had a quiet day. His responsiveness continues to decline.*

#### OCT 16 (FRIDAY)

*Paul is much more alert compared to yesterday. He can still move his arms and legs but probably not for too much longer.*

#### OCT 17 (SATURDAY)

#### OCT 18 (SUNDAY)

#### Oct 19 (MONDAY)

#### SEASON'S HOSPICE, ROCHESTER

*Baptism of Grayson*

Monday evening, I got a call from Dad saying that Paul has taken a turn for the worse and the nursing staff said that the end is near. I left Eagan about 2:30 am for Rochester.

#### OCT 19 (MONDAY OVERNIGHT)

#### SEASON'S HOSPICE, ROCHESTER

The sky was clear with a nearly full moon and with very little traffic on the highway making for a remarkably peaceful and quiet drive. I decided to avoid the disruption of driving through the city by taking the back route to Seasons Hospice. Desolate county roads lead right to the long driveway of the hospice. I dimmed my lights and drove slowly down the driveway preparing myself for what may have happened in the last few hours. At first it was difficult to make out what was going on in the parking lot. A white cargo van was backed up to a wide-open front door. Seems like an odd time for a delivery. My lights then shone on two staffers pushing a gurney with a wrapped dead body strapped to it.

What do I do? Do I slide it into reverse and quietly back out? Do I act naïve and clueless? Do I do the guy thing and crack a tasteless joke? Having neither my joke book nor a copy of Miss Manners on me I proceeded with my dimmed but still shockingly bright lights aimed right on the action. They froze as clearly, they were not expecting anyone at this hour.

I pulled into the space next to the van and opened my door, so they could see me. One of them said to me "Oh, your Paul's Brother". They swiftly loaded the van as if they had done these a hundred times and then rapped on the back of the van and said to the driver "your good to go". The van disappeared into the blackness within seconds. I procrastinated a little by gathering my things from the car, but the front door remained propped open.

A trail was illuminated to the supply closet and down to a patient room. Clearly this is the preferred hour for dealing with death openly and candidly as they prepared the room for a new patient.

The hospice staff have created an environment that embraces death without being creepy. I felt alive and at peace while surrounded by people waiting their turn to die. There is no undertow of angst and hopelessness. There aren't any happy shiny people in denial. Just real people dealing with seemingly conflicting daily events of life and death in a matter-of-fact way that the events themselves don't hinder their ability to serve others who are struggling to cope with these events. It takes a special person to do things like repositioning a person's body and limbs every hour or so to ease the dying process. They are doing what is practically needed and fly's in face of our western culture that would either respond to this situation with medical heroics or sheepish disengagement.

Paul's room is next door to where all the activity took place. No drama here. Paul is sleeping soundly and peacefully. I decided that both Paul and staff would be best off if I left for a little while and had breakfast.

## OCT 20 (TUESDAY)

## SEASON'S HOSPICE, ROCHESTER

I returned by 6 am and set up shop in Paul's room. It was difficult to watch television during his increasingly labored breathing. Should I turn the TV off and soldier through this? Or is it time to retreat by letting go of the notion of being here with him? I believe both are possible if we shed the world view of 'us' and 'them'. Instead of seeing the world as a collection of individuals, we see the plurality of individuals as one cohesive system. To see the world as a system is to begin to understand creation itself and this is the essence of my being.

When a hospice nurse intuitively picked up on my predicament a wonderful solution began to emerge.

We setup a working table for me in a public area that had a service door to Paul's room. I was all set with a dimmable lamp to work by, hot coffee, cold water, snacks, and a large window to the scenic backyard. Paul was more in his element with indirect lighting, no blaring television, and his brother close by but not too close. She asked me to pick out a CD that she could play for him. Now here is the brilliant – albeit subtle - part. She positioned the openness of the door so that I could hear Paul in way that I would not be listening to Paul. (It reminded me of a Mom putting her kid to bed while entertaining friends – by opening the door ajar she could remain vigilant without having to choose between *being* a baby sitter or *hiring* a baby sitter.)

The nurse periodically stopped by to tend to Paul's comfort and to tend to my comfort. Let me spell this out. She was not tending to the needs of two people! She was tending to the needs of the connection of two people. I don't think she differentiated between patient and visitor or was concerned about life and death – she was focused on the here and now that my brother and I were sharing. Truly remarkable. Remarkable that she had the skills and chutz pah to do this. Remarkable that I found peace as my brother struggled to breath just a few feet away.

In retrospect I am a bit disturbed by the fact that I did not find it at all disturbing to be literally waiting after each of his breath for the silence of his last breath. There won't be some dramatic conclusion to this. The only thing that will happen is that he won't take another breath which is to say that nothing will happen which is to say that everything will happen – for Paul! As for me it is all about the presence of breathing – not absence – which is the one thing we still have in common. Tend to the breathing. The breathing of our connected body's during this time of great transition.

The entire day was consumed by visiting with Peter, Mom and Dad.

About 4 pm the house nurse asked me how Kathy and my Mom are going to deal with this. She said that she is not sure how these two will react to what will very likely be Paul's death in the next 24 hours. She asked me to tell Kathy to cancel her daycare tomorrow; she should not be tending to kids when this happens. Fortunately, Kathy arrived an hour later so she could talk with the house nurse directly.

Paul was in a daze and for the most part unresponsive. He did not eat, take meds, or show any signs of recognizing people in his room. I spent the afternoon in Paul's room along with my parents. There were a couple of brief visits from clergy and family but that gave way to an awkward couple of hours of death watch. My Mom was stoic and was sinking deeper into the corner recliner.

Naturally Dad carried the conversation and went on several tangents of friends of his who recently died. He and I spoke with a staffer at St. Mary's Hospital for a couple of hours about Paul's level of consciousness and the process of how he communicates with others. They were in complete agreement with me that at some level Paul can comprehend the immediate...but open-ended questions, overheard conversations, and too many people in the room all likely caused him stress since he could not make sense of it. They recommended telling Paul one simple statement from one person at a time. It could take up to a half-hour for him to ingest it and another half hour to formulate a response. He could then nod his head or smile; however, it could take a half hour or more for him to figure out how to speak a response. This last part can be quite exhausting for him and would often result in poor word choice leaving Dad to think that he is just speaking gibberish.

I mentioned that Paul hated medical talk. Dad said that he was going by what the surgeon told him last week. Paul was like a 3-year-old and had no memory five minutes after talking to someone. He saw no problem discussing things in front of Paul and figured that it was OK to have a continuous stream of visitors each day. I reiterated the conversation I had earlier with a staff member. She said that at some level Paul would have awareness until the very end and that medically the hearing is the last to go. Even with a patient in a coma, it is better to assume they can hear and not say anything inappropriate.

As Dad rambled on it was clear that my attempt to sway his opinion would merely add more medical type talk for Paul to hear. So, I simply interrupted him and respectfully requested that he take that conversation elsewhere. He complied but now without the distraction of long story telling it got very somber. Mom was now comatose. Dad was on the brink of a breakdown. It was so clear to me what I needed to do.

Paul is ready to die. Like he had the car packed and said, "I will be in the car waiting!". He was not about to leave without everyone onboard, but he was also not about to linger behind. He is packed and ready to leave now.

For the past two weeks Paul, has been more than just the center of attention, he has been entertainment for dozens of visitors. He needs to be free of this burden.

He is not going to abandon family...especially Kathy and my Mom. He needs to know that we will be OK.

I talked to Mom. I told her that she has every right to be angry at God. This is not the natural order of things. You should not have to see your own child die. You have been cheated! Moreover, you dedicated your life to raising us and your job was not only over many years ago, but you should now be basking in the pride and joy of a new great grandson. You should be looking to your grown children when you need a little help, certainly not the other way around. This is nothing short of a rip off.

I then told her that none of that matters right now. Like it or not you need to be Mom again. You have to step up to the plate and do this. You know what Paul needs to hear and he needs you now. You need to do this!

Dad was a bit taken back as he stated that Paul can't comprehend anything. Then Mom on her own volition got up from the recliner, brushed (shall we say decidedly pushed) Dad aside as she marched toward Paul's bed with resolve. She grasped his arm and said "Paul it is your Mom. We will be OK...you go live with Jesus... <could not hear these words>...sweetheart. You go ahead now. I want you to be with Jesus."

That was it.

She turned around and sat down.

I affirmed to her that she said exactly what Paul needed to hear. It was just that simple.

Kathy soon joined us.

Everybody knew that tonight would be the night. Each person voiced their wishes for seeing Paul. Some wanted to see him after death. Some wanted their final goodbye to be right now. I was a little surprised and relieved that everyone wanted to be home and get a phone call at the time of death. I wanted to stay the night and take it as whatever may come. I got the feeling over the past two weeks that Paul wanted the dignity that comes with privacy from onlookers...but was OK with just me being there at night.

About 9 pm as everyone was heading out the front door in comes Brian from church. He said that he has been stopping by every day and just needed to come out one more time today. The group talked rather loudly until almost 10 pm. During this time, I shuttled several suitcases from my car past the gathering by the front door to Paul's room. These brief encounters with Paul were shocking. I could see him dying before my eyes. It is as if he was holding out until everyone left and then switched into death mode. His face and arms were grey. I touched his cheek and it caved in. He was barely breathing. I made a few hints that everyone should go home trying to gently imply that they are about to miss 'the phone call' they expected to get at home tonight. In talking with a nurse, it seemed just an hour or two away.

As I settled into Paul's room it got weird quick. Paul did not want to die in front of me. And I did not want to make this freak show in either of our eyes. I left my stuff setup in his room but went back to the table in the adjacent area.

I heard the last of the crowd upstairs as they left for home.

Then Brian came walking down the stairs just outside of Paul's room. I began walking up the stairs as a somewhat passive means to protect Paul's privacy. I could tell that he was more than just concerned...he was grappling with how he should last see Paul. We talked for half an hour loud enough where Paul would be able to hear us. Brian said that he does want to see Paul one more time. As we walked into his room I said that Paul is not looking good. Brian was bewildered on how Paul could have declined so dramatically in just one day since he last saw him. His mouth was now wide open, and head tilted back. His arms were at vertical right angles to his body with wrinkled

grey hands in an acute and unnatural bend. He was breathing very heavy and labored at a regular rhythm. This was nothing like just an hour ago. It is as if he started to die and changed his mind when he heard the voices upstairs. He was not about to make a spectacle of himself for others.

#### OCT 20 (TUESDAY OVERNIGHT)

#### SEASON'S HOSPICE, ROCHESTER

A little after midnight Brian and I sat at a table just outside of Paul's room thinking that he would resume his previous more peaceful process of death. We talked for a couple of hours and had a wonderful conversation. Paul got much worse. His breathing was so disturbing that he could be heard on both levels of the house with Brian saying, "Just give it up Paul!". It was now past 3 am and we were so focused on his breathing that we could have taken wagers on when it will "skip a beat" and if there will be another breath after that. Got a little freaky and that resonated with me. He was still fighting with each breath because of our presence!

Paul's nurse said that he has a strong heart and can fight this for a long time. I asked Brian what he thought about leaving for a while so that Paul could have a couple of hours to himself. It seemed to me that if he was wanting privacy to die then he would do so within an hour or two, otherwise he seemed to have enough stamina to make it well into the morning when we would return. Brian agreed.

A nurse tended to Paul by massaging his neck and arms and then carefully repositioned him with several pillows supporting his rather rigid posture. His breathing was much less labored and resembled the timbre of earlier in the evening. There was an awkward tension for us - on one hand it was good to see him less stressed, but on the other hand it felt like we are protracting his final hours.

This was a clear sign that we should go home.

I left the hospice at 4:15 am. I did not feel any need for "last time I will see you" thoughts. I focused on packing my things up and taking care of myself during the ride home. I got home at about 6 am and immediately fell asleep.

#### OCT 21 (WEDNESDAY)

Dad called me a few minutes after I fell asleep to tell me that Paul had just died.

Those at the hospice said that people often choose the timing of their death. I had every intention of being with him until his last breath, but this is not what we wanted. I am convinced that he would have passed away hours earlier if he had not fought and persevered until the time was right for him. Which is to say that the time was right for those close to him. Everyone was safe at home and nobody was lingering around to gawk at him – except me. It is remarkable that he chose 6:10 AM to pass away. That gave me just enough time to drive back home in Eagan and this is the time that Kathy normally has her alarm set to get up for the day.

So, Paul was ready, but waited until...

...everybody was safe

...everybody was where they wanted to be

...he had a little dignified privacy

That sure sounds like Paul!

**All the days ordained for me were written in your book before one of them came to be.** (VERSE 16 NIV)

We can never know if life events are "written before we are born" or are left to free will. Seems easy enough to find out, but there is a catch. We would need to know the preordained time before such an event occurs, which in the absence of a T-1 line to God, is not going to be coming our way. This is what faith is about. It is not important to prove God's intent to ourselves and others – it is more about how we choose to live our lives in context of such dichotomies.

All we know is the actual time Paul died. Would he have died at that moment regardless of our actions that night? I am personally convinced that Paul did chose when he died and that was influenced by those whom he loves. Makes sense to me...he had the hand of Jesus while still occupying his deprecating body and made the transition that he needed. God no longer has a set of hands here on earth, so it is up to each of us to put miracles in motion. I firmly believe that I did what I had to do to ensure that Paul could die when he did. Preordained or not. It is a moot point. The universe always delivers exactly what it should. Paul died not a minute before nor a minute after when he should have. If he was to die at 6:15; then he did die at 6:15. If he did die at 6:15; then he was to have died at 6:15. Faith will not get one iota stronger or weaker by (at)tempting to prove our faith with physical evidence.

## FLORAL ARRANGEMENT

Oh, what to do. My Sister thinks that I can order funeral flowers all by myself – just call an 800 number – they will know what to do. She can't be serious. Nothing is that easy in my life!

I want to design something unique just for Paul, but I don't see how a local florist can be motivated to do that when 'corporate' passes down marching orders and retains a hefty commission from their pay. What I need is a traditional mom and pop type florist that works with a client to create a unique floral design. After searching for a couple of hours I came up empty handed. It was disheartening to discover that virtually every floral shop that had the appearance of being independent, had sold out to the 1-800 corporate veil.

Then I stumbled across a true gem. The Flower Shop in Blaine. It was well worth the drive to work with these artisans. Taken from their website:

*We are a tiny local florist with sassy one-of-a-kind arrangements by three dedicated employees.  
(If you're looking for dull & unexciting, go somewhere else.)  
We are blunt. It saves time.*

*"Now may the Lord of peace himself give you peace at all times and in every way. The Lord be with all of you." -2 Thessalonians 3:16*



When I called the florist, they did something so fundamental that it was amazing – they listened with an open mind to my ideas. I wanted to use some of the organ pipes that Paul gave me many years ago from an organ he was going to restore. It was also important that the flowers not be too morbid or flowery since Paul hated that sort of stuff. We chatted for quite a while and then they simply ran with it - delivering a unique work of art just for Paul.

Picking up the flowers was an experience to behold. One of the owners spent well over an hour with me after store closing time.

She was very concerned about how I would be transporting the arrangement since this would usually be done in their cargo van. We measured earlier in the week, but it was a very tight fit in my 4Runner. She carved a large box into a custom carrier that would protect the floral spray up until funeral time. We practiced loading and unloading my vehicle three times before she was satisfied that no flower stem would be compromised during the drive home, a night in my garage, the drive to Rochester, and hauling it into the church. She was adamant that everything must be perfect for my brother. As she worked we talked liberally about life, death, owning our businesses, and the devastating impact that the corporate 1-800-FLOWERS/FTD industry has had on small florists. Virtually all florists today are associated with the FTD umbrella, but those who try to retain their locally established

clientele end up being leveraged out. It is remarkable that The Flower Shoppe is completely independent – but she said that there is no other way. Accepting FTD referrals is a one-way street to selling-out your business.

When I was ready to go she motioned for me to come back into the store. She went to a large cooler and carefully selected a single rose. She took it over to a workbench and fashioned it into a small arrangement. She wrapped it up and said that this is for you. Very touching!



I awoke early with an idea of how to honor Paul at our traditional Thanksgiving dinner. This will be the first holiday without him. I needed to lay my hands on two dozen yellow roses with red tips – not the easiest thing to do on Thanksgiving morning. Then I called Fisherman's Inn and asked the owner to make an extra place setting at our table for Paul and for waiter to come to our table specifically to take Paul's dinner order (knowing that I would be ordering Filet Mignon for him and that the meal would be packaged to go) – not the most welcome call on one of their busiest days for the year. Lastly, I called Kathy and asked her to bring something of Paul's – his hard hat, or a jacket.

As we each arrived and claimed a spot at the table, Kathy symbolically claimed a spot for Paul by putting his coat over the back of a chair. I then took his silverware and crossed it over the place setting and turned his water goblet upside down to signify that he would not be participating in food or drink.

As we began eating I handed each person a yellow rose with red tips to symbolize "sorrowful joy" – the dissonance of missing him while knowing that Paul is indeed in a good place.

My plan was to place an order for Paul's favorite meal and encourage each of us to symbolically place our flowers on Paul's place setting and thereby literally choosing joy over sorrow on this day of thanks. Clearly this was getting too much for a public setting, so I postponed it until we got to Mom and Dad's house.

*Paul is no longer of the flesh that needs constant nourishment - he has no use for this meal.*

*Paul is no longer of a sinful world separated from our creator - he has no use for our sorrow.*

*Let's give Paul what he needs from us - our joy for his eternal redemption over death!*

*His food and flowers will be taken to an individual truly in need of nourishment and hope on this day of thanks.*

## KATHY'S DREAM

### SWEET CAROLINE – NEIL DIAMOND

Where it began  
I can't begin to knowing  
But then I know it's growing strong  
Was in the spring  
And spring became a summer  
Who'd believe you'd come along  
Hands  
Touching hands  
Reaching out  
Touching me  
Touching you  
Sweet Caroline  
(Duh Duh Duh)  
Good times never seemed so good  
I've been inclined  
To believe they never would  
But now I  
Look at the night  
And it don't seem so lonely  
We fill it up with only two  
And when I hurt  
Hurting runs off my shoulders  
How can I hurt when holding you?  
One  
Touching one  
Reaching out  
Touching me  
Touching you  
Sweet Caroline  
Good times never seemed so good  
I've been inclined  
To believe they never would  
Oh no no  
Sweet Caroline  
Good times never seemed so good  
Sweet Caroline  
I've believed they never could  
Sweet Caroline  
Good times never seemed so good  
Sweet Caroline

### SISTER GOLDEN HAIR

Well I tried to make it Sunday, but I got so damn depressed  
That I set my sights on Monday and I got myself undressed  
I ain't ready for the altar but I do agree there's times  
When a woman sure can be a friend of mine

Well, I keep on thinkin' 'bout you, Sister Golden Hair surprise  
And I just can't live without you; can't you see it in my eyes?  
I been one poor correspondent, and I been too, too hard to find  
But it doesn't mean you ain't been on my mind

Will you meet me in the middle, will you meet me in the air?  
Will you love me just a little, just enough to show you care?  
Well I tried to fake it, I don't mind sayin', I just can't make it

Well, I keep on thinkin' 'bout you, Sister Golden Hair surprise  
And I just can't live without you; can't you see it in my eyes?  
Now I been one poor correspondent, and I been too, too hard to find  
But it doesn't mean you ain't been on my mind

Will you meet me in the middle, will you meet me in the air?  
Will you love me just a little, just enough to show you care?  
Well I tried to fake it, I don't mind sayin', I just can't make it

Doo wop doo wop ...