



NOBODY LOVES ME LIKE YOU DO

By Keith LaMotte

*An ALS caregivers story about living, loving,
laughter and leaving a legacy.*

a memoir

FOREWORD

First, let me explain that I am no writer. I am a husband and father who has tried to put on paper his experience in hopes that maybe some other friend or family member of an ALS victim will hold on to some small piece of information in this book that will make their journey with ALS a little easier.

I guess I need to explain the origins of the book. Why did I write this journal? I guess I started to write this book simply as therapy for me. I started writing three weeks after my wife Diane passed away from ALS (Lou Gherig's Disease). At first, I figured maybe this would be a good way to document my life with Diane for our daughter Amanda to read and reflect on as she got older. Then I realized that through my writing I was able to deal with the "grief" and the aftermath of her death a little bit better.

As the book developed I realized I wanted to tell a love story as well as produce a literary document of what it is like to care for an ALS patient and the decisions one must face that are truly life threatening. As a primary caregiver for my wife Diane, and having experienced just about all that ALS can throw at you, I feel quite qualified to give advice. But most of all I'm here to tell our story.

The first third of the book is the story of how Diane and I met and fell in love. It includes some of the stories of being in a Vegas Style Show Band and touring the country. As entertainers, Diane and I made choices that eventually brought us to Orlando and together we raised a family and started two successful businesses. However, I have opted to not include this section of the book at this time. The reasons for this vary but the number one reason is that the purpose of the book (at this time) might be overshadowed by our early years escapades instead of the ordeals, conflicts and life altering effects of an ALS family.

The last two thirds of the book (written here) includes the day to day experiences of caring for an ALS victim. It is a "no holds barred" documentation of what it is really like to "cope" with ALS. In facing this devastating disease, Diane and I had a choice of being bitter or confronting, acknowledging and fighting this menace. Everywhere we looked either on-line or in books no one really told us the way it would be. No one wanted to tell you the dirty part of this disease. I wish I had read something like what I have written so I would have been better prepared for the future progression of this dreadful disease.

I hope I captured in my writing the way Diane and I approached and ultimately dealt with this disease. Mostly, we used humor and open communication to get us through this part of our lives. Having experienced the journey that ALS takes you has been the hardest thing I have ever done. At times I didn't think I was up to the task but because I loved my wife so much I never gave up, for as bad as it was for me it was a million times harder for her. But she never wavered in her optimism for the future and joy for the present moment even though we both knew what the end result was probably going to be.

The title "Nobody Loves Me Like You Do" has many meanings to me. Mainly, it was Diane's and my unofficial "song". It was recorded by Whitney Houston and Jermaine Jackson and was a love duet from the nineteen eighties. Diane and I sang it quite often while performing and it was one of those songs that we always connected to each other every time we sang it. We always fell in love with each other a little more every time we sang it to one another. It was also the last song we ever sang together on January 1, 2003.

If you were to visit her gravesite you'll see the marker with the inscription of "Nobody Loves Me Like You Do" along with two Trumpets representing both of us as players of, and our love for, the Trumpet. But the title also means exactly what it says. Diane loved me like no one ever has and I loved her more than anyone has ever loved her. The words just say it all.

I have omitted quite a lot of time and information in this manuscript, not because I didn't want to share it but because of money. This book is being published on a shoestring budget and the amount of pages has a strict correlating effect to the cost of the book. All proceeds from the book go to the "Diane LaMotte ALS Foundation" which was founded to provide necessary needed equipment for ALS caregivers and respite care funds for Central Florida ALS families. I make absolutely nothing on the proceeds of this book. So, plain and simple, this book is a fundraising instrument for the foundation. So support us by spending a few dollars to purchase this book and help us help families that have lost or could be on the verge of losing everything they have worked so hard for their entire lives. And by supporting us you help us make a difference in the care of their loved one with ALS.

I have tried to be as accurate as possible of the timeline in Diane's progression. I have forgotten when certain things happened but I haven't forgotten what happened. If my time sequences seem random at times I apologize, I just can't be one hundred percent certain of what crisis came first or second. Most of the time these crisis episodes happened within days of each other so that might account for my confusion.

Again I'm not a writer but a simple man with a story, a "love story" called "Nobody Loves Me Like You Do". Enjoy!

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Nobody Loves Me Like You Do

By Keith LaMotte

It was a hot afternoon in July 2001 when Diane got a call from the Azury Talent agency informing her that Amanda was being offered the lead role of “Emmy” in the PBS TV show’s national touring company of “Dragon Tales”. The three of us were stunned and excited. This was to be a nine month tour (which actually lasted 12 months) starting in Minneapolis, Minnesota and supposedly ending in New York City in June 2002.

As we got details on the tour our heads started to spin. Should we let Amanda do this? What about school? Her friends? Our family? This would mean that Diane and Amanda would be gone, leaving me alone in Orlando. At first I thought, “Great, I will be the King of the TV remote”. The two of them always hogged the family room television, watching the Disney Channel or Diane’s favorite, “Emerill,” on the Food channel. I had overdosed on both channels to put it mildly. Despite my interest in controlling the remote, I wasn’t sure the tour was for the best. But as was our habit, everyone in the family had the opportunity to voice his or her concerns, fears and worries. I truly wasn’t sure what was best, so I did one of the two things I always do when a tough decision has to be made. I mowed the lawn (the other is to take a long hot shower). Diane and Amanda had voted to do the tour. They were pumped up, excited and ready to go. Now it was up to me.

So, I got on my Snapper riding mower and started cutting grass. As I rode, I realized how big a decision this was. The two most precious people in my life would be away for nine months. I hated having them away for nine hours, let alone nine months. But I knew that this was an opportunity for Amanda to shine on stage. Moreover, she’d get the experience of “going on the road” and all it has to offer. Amanda had listened for years to Diane’s and my road stories, and now here she was being offered a similar experience.

I sensed that this decision would change our way of life and our family forever, but at that time, I had no idea just how much it would affect us all. I knew that the Dragon Tales gig was a once in a lifetime experience for this mother and daughter to live and travel very closely together, and to experience the many cities that they would visit. I felt they had to do it, no matter the sacrifice Diane and I had to make. So I pulled my mower up to the pool screen and waved to Diane in the kitchen to come out and talk to me. I told her that as long as Amanda’s school, Trinity Prep, gave its blessings to this endeavor; I thought they should do the tour. Diane agreed and so we started preparations to accept the job.

The next day I called Craig Maughan, the Headmaster at Trinity Prep, and explained the tour and job offer. Amazingly, he said the school would work with the tour’s tutor; he thought the opportunity was too good to pass up. Meanwhile, Diane worked the agents and Vee Corporation (the Dragon Tales touring company) to negotiate the best contract for Amanda, to get all the rehearsal dates and touring requirements. This was quite a job, and we were working down to the wire to make sure they both had what they needed before they left Orlando for their rehearsal city, Minneapolis.

Earlier in the summer I had been offered a unique part-time job myself. A company out of Seattle needed a spokesperson to visit videography associations around the country and talk about DVD duplication and try and promote their DVD burning company called Homemovie.com. This was a very clever internet company that took wedding video, sports video and general home movies and burned the VHS video to DVD. In my opinion, it was

a magnificent company run by very bright and talented computer geeks. I was to start flying around the country about the same time Diane and Amanda left for rehearsals.

The day they left Orlando will be forever etched in my memory. It was September 7, 2001. Talk about a day to remember. I cried all day. Now please take notice, the date was four days before 9/11 and you could still walk passengers to the gate. The three of us stopped for some food before making our way to the gate. I captured all of this on videotape. Watching the footage brings back the all the emotions of that day.

Saying goodbye to my daughter and my wife was one of the hardest things I ever had to do. I knew deep in my heart that our lives were about to change so much, and though I knew it should be a very positive thing, something seemed very unsettling to me. I cried all the way to my car, which was parked in the airport parking garage. I drove up to the top level to where I could see their plane still parked at the gate. Eventually, it backed out and started to make its way to the runway for takeoff. I cried like a baby. I missed them already and wanted them back. They were no doubt excited and laughing and getting ready for their new adventure, but Dad was crumbling as the plane rolled down the runway. I watched the plane takeoff and I continued watching till the jet became a speck and faded away. Diane and Amanda were gone and I was all alone. I hated it already.

Now, being the worrier that I am, I couldn't wait for them to land, connect with the person meeting them at the airport and then get settled in to the hotel. Those few hours seemed like days, but eventually Diane called. Everything had gone smoothly. They had already met some of the cast and were in the hotel. I tried to relax. I admit that I was way over the top emotionally.

For the next few days Amanda was in her element. Bonding with the cast, memorizing her script and learning the songs dominated her waking hours. Diane said she was loving the work and putting everything into it. This didn't surprise me one bit. Even at the age of twelve, she was a consummate professional.

On Tuesday morning, September 11, 2001, I woke up and reached for the TV remote. As I did, I got this incredible sense of uneasiness, so much so that I was reluctant to turn on the TV. Still, I switched on the Today show, only to see that they were trying to figure out what was happening at one of the Trade Center buildings. Like millions of others in the USA, I watched in horror as the events of that day unfolded. As it became clear that this was a terror attack, I was overcome by worry, and I immediately got on the phone to Amanda and Diane in Minneapolis. They had just turned the TV on as they were preparing to leave for the first day of full cast rehearsals. For the next half hour I spoke to them via cell phone and kept them up to date on what was happening while they were being shuttled to the rehearsal venue.

Somewhere along the line, reports started coming in about an arrest in Minneapolis of a terror suspect. This really freaked me out, Amanda and Diane were in the city where one of these idiots was on 9/11. Fortunately, Amanda spent all day rehearsing and was somewhat oblivious to what was happening in the world that day.

For the next several weeks the Dragon Tales rehearsals continued and the country got back to a new "normal." I was one of the few who were braving the airlines and flying to different cities to "speak." It was very strange to be one of about ten people on a big Boeing 747 airplane. Eventually, however, the planes became very crowded as the airlines cancelled flights and doubled and tripled up the passenger lists.

On October 4, 2001 I flew to Minneapolis for the opening night of Dragon Tales "Missing Music Mystery" at the Target Center. This was also Amanda's 13th birthday. Just before the show started the cast got together back stage in the dark and sang "Happy Birthday" and had cake with Amanda. Then it was time for everyone to find their

places. Diane and I went in to the arena to find our seats. When I walked in I was overtaken with emotion. I realized that my baby was about to embark on a tour where she was the star of the show, performing before thousands each night. As I sat down I looked around at about fifteen thousand people being seated for the show. I think I was more nervous and anxious than Amanda and Diane combined.

As the house lights lowered, one of the most memorable events in my life took place. Diane put her arms around me and smiled. Her gesture surprised me, I wasn't sure why. But then the stage was flooded with light and there was my little girl, and I suddenly understood why Diane was holding me. She knew how the opening was going to affect me. Amanda was all by herself on stage, playing the piano, singing a song and starting the show. I lost it. Tears just exploded down my face. I overdosed on parental pride.

For the next hour and forty minutes I watched my daughter and the Dragon Tales cast perform a high-energy, musical production. Amanda sang, danced and acted like she had been doing this "gig" at this level her entire life. Diane, as was her way in these situations, just kept her emotions and words to herself. She just smiled and drank it all in.

For the rest of the fall 2001, Amanda and Diane traveled with the cast of the show to a different city each week. In most of these cities Amanda was interviewed on the radio, on TV and the local newspapers. One of the highlights was when they were driving to one city's venue and they looked up and saw a billboard with Amanda's picture on it, advertising Dragon Tales. We have a photo of that billboard.

On Christmas Eve, Amanda and Diane returned home for the holiday break. It had been over two months since I had seen them, and I couldn't wait for them to come home. I had all kinds of things planned to make their stay special. Probably the most fun thing was what I called a "reverse surprise 40th birthday party" for Diane. Her birthday is January 14th, but since she and Amanda would be back on tour, I wanted to surprise her with an early celebration. A couple of days after Christmas, I had told Diane that we and another couple were going to dinner. I had even rented a limo to take us. But first I thought it would be nice to have hors d'oeuvres and drinks at the house. So Diane did her typical preparation of nibbles and cocktails for us. Well, as I had set it up, people started stopping by. One by one, people kept knocking on the door and saying they were here for the limo and when were we going? Diane was truly bewildered, and then visibly panicked at the prospect of not having enough hors d'oeuvres. I reassured her that "We're fine, don't worry about it," but gracious hostess that she was, she was very uneasy. Only after one of the guests came in and said "Happy Birthday!" and we all laughed, did she finally figure out this was a party for her. She was shocked. Then she said "but we have no food". At that point, Amanda, friends and I started pulling out food, decorations and drink that we had hidden, and in about twenty minutes, we'd turned the house in to a full blown party. All Diane could do was watch and laugh. She enjoyed herself so much that night. Some of my favorite pictures of the three of us were taken that night.

And then, so fast, the holidays were over and Amanda and Diane left for Baton Rouge, Louisiana, to continue the tour. I dropped them off curbside at Orlando International Airport with four very big suitcases. Later I found out that they had to move all four suitcases through security checks and had to take everything out for inspection. This took its toll on Diane's back and by the time they arrived in Atlanta for their connecting flight, she was in major pain. As luck would have it, a snow storm hit and grounded all west-bound flights. Half the cast found each other in the Atlanta airport and waited out the delay for 24 hours. Meanwhile, Diane was given a wheelchair. Her back hurt so much she couldn't walk. They finally arrived in Baton Rouge, and from what Amanda later told me, Diane was in lots of pain. Eventually she recovered, but from that time forward she started to show some very unusual traits in her walking and her body.

Now let me say here that I didn't learn any of the following until about nine months after the fact. While on tour,

Diane found herself repeatedly stumbling or "stubbing her toe." After a time she said something about it to her friend, Anne Marie, who was a frequent visitor, but they both blew it off to fatigue. But what Diane didn't tell anyone was that she felt some "twitching" in her left knee and ankle. This twitching wouldn't go away and in fact, would grow in intensity. This was around March of 2002.

During this time I was traveling all over the United States and, as I said, knew nothing of any of this. In March, I traveled to Atlanta to spend a few days with Diane and Amanda. Everything seemed fine. I didn't notice any signs of trouble with Diane and she didn't mention any problems. In June, I traveled to Baltimore for a one day trip to see the show with all my family in Maryland. As we were leaving the arena, I noticed Diane limping and asked her about it. She said she didn't remember injuring herself. I asked her if it hurt and she said "no it didn't". I found it odd that she limped if nothing hurt, but I dismissed the incident from my mind completely. I later found out the "twitches" were increasing in frequency, getting stronger, and moving to other parts of her body.

I next visited them over the July 4th weekend for a four day vacation. Amanda had just closed at the Continental Airlines Arena at the Meadowlands in New Jersey. I rented a lakeside cabin in the Pocono Mountains. It was beautiful, and we had a great time boating, eating and horseback riding. It felt good to be a family again with no show or business interference. The cabin had two front steps to get up on the porch. Diane struggled with these steps. I didn't say anything to her but it bothered me. She looked really ragged, like she wasn't taking care of herself at all. She was also significantly overweight, so I attributed the limp and the trouble climbing stairs to the weight gain. After the short vacation I took them both to Bethlehem, Pennsylvania, where Amanda was to perform. On one of these days Diane and I went to the local mall. On the way there we had a big argument. I really don't remember what started it, but quite a bit of it was me telling her how horrible she looked and asking why she wasn't she taking care of herself on the road. "What kind of impression was she making on Amanda, looking this way?" I asked. Then I said something I will never forget. I said, "Look how you walk. You walk like an old woman". Now I know why she walked that way, but at the time we were both in the dark.

On the fourth of July, most of the cast walked to a bridge from which we could watch fireworks being set off. Diane struggled to get there and was the last to arrive on the scene. But as was her nature, she laughed and partied and showed no signs of concern. Now however, I believe she was deeply troubled by what was happening to her. She just kept it to herself.

By this time, the nine month tour had been extended to twelve months and that meant they wouldn't get back home to Orlando until September 1, 2002. I picked them up from the airport almost one full year from the day they left. Amanda was a wreck. She wanted to stay on tour. Even today, if the opportunity to go back on tour presented itself, she'd be gone. The road is in her blood now, and speaking as a road musician myself, I can say that it always will be.

As soon as we arrived home Diane went on line and typed in her symptoms to the www.webmd.com web site. Immediately it said she might have "Lou Gherigs Disease" or ALS (Amyotrophic Lateral Sclerosis). She then searched the web to find out more on this ALS disease, and came up with a site that begins by saying "if you have been diagnosed with ALS, be sure to start writing your will now". Well Diane and I just laughed and blew it off. Neither one of us, or maybe I should say, I didn't think there was anything major wrong with her. She couldn't be sick. She was way too young. This was Diane, my tower of strength, the world's most terrific mom and everyone's friend. She had just returned home and we had plans. We were both going to buy motorcycles, fix up the game

room and remodel parts of the house. We were going to date each other again. Diane couldn't be sick. No way Jose!

The first step to figuring out what was wrong with her was a trip to a Chiropractor. He advised her to see a neurosurgeon, which she did sometime in October 2002. I was in Columbus, Ohio about to get on an airplane to come home when she called my cell phone and told me that the doctor thinks she may have a brain tumor and that she was to go immediately across the hallway for a CAT scan or MRI. This was the first time I realized Diane had something truly wrong with her. That was the longest flight of my life; because I was in the air, I couldn't make or receive any phone calls. Was she okay or not? It was maddening not knowing what was happening to her.

When I finally got off the plane, she told me that they didn't find anything wrong, but advised her to see a neurologist as soon as possible. She did a week or two later. I asked her if she wanted me to go with her, because I had learned that the EMG test that they were likely to perform was alleged to be quite painful. She said she had read it was no big deal, and that she'd be fine. So off she went that fateful day, November 7, 2002.

It was about 4:30pm when the phone rang. On the other end was a hysterical voice that at first, I did not recognize. Eventually, I figured out it was Diane. I'd been with her for nineteen years and had never heard her even close to this upset. First I told her to pull over. Then I asked "What's wrong?" I thought she had been in an accident or had seen something horrible. She replied, "The doctor thinks I have ALS, Lou Gherig's Disease!" I was stunned. She was hysterical. All I could think of was that website where the guy wrote about start writing your will now. I talked with her until she calmed down enough to drive home. I waited and waited for her. For some reason it was taking longer than usual for her to drive from Maitland, Florida where the medical offices were. When Diane finally got home all we could do was hold each other and cry. We didn't know what we were in for but we knew it was bad. Real bad.

That night Amanda had a school dance. We were both supposed to pick her up at school and have dinner, then take her back to the school dance. Diane wasn't up to it so I went instead. We had agreed not to say anything to Amanda until we had a second opinion. This was a very hard dinner to have with my daughter. I was a wreck and very emotional but had to look okay for Amanda. Fortunately, Amanda's drama teacher and Diane's close friend, Janine Papin, was there at the restaurant and had dinner with us. I told her what was going on. She was the first to know other than Diane and me. As time would go on, Janine would be major support for Amanda and Diane through this ordeal.

The next day, November 8, 2002, was supposed to be a great day for us all. I was to sign a contract with the local TV station to air our new TV show, and Amanda and Diane went to Universal Studios to start a four day shoot for the "Kidzbop" Video. Needless to say, I was in such a state of shock that I cancelled the contract signing. Diane and I weren't sure about anything at this time. She did take Amanda to the shoot and had to stay on location at Universal Studios for twelve hours a day for four days. This is how Diane spent the first four days of knowing she had ALS. Basically, she had no phone contact, no internet access and no emotional support. She needed to be tough and "mom" to Amanda while "on the set".

During this same time I started researching everything I could find on the internet about ALS. Everything I read was depressing. I cried and I cried. I couldn't believe this was true. This couldn't be happening to Diane or our small family. They were fresh off the road, we were starting a TV show, and Diane and I were falling deeper in love.

I had realized early on the tour how much I missed Diane. She had been by my side for nineteen years at that

point. Through thick and thin she was my greatest support and the wise voice I always needed to hear. I hated the lonely nights without her. I hated not being able to go in to her office and talk with her about business. I missed the great dinners she fixed most every night. When she was back home we felt like kids dating for the first time. We couldn't keep our hands off each other. It was nice. We laughed and talked about the future of the business and phase III of the house remodeling project.

Now all of that was pushed far away in the recesses of our minds. What was ALS? How come some people are only inconvenienced by this disease while others die from it? What treatments were there? What drugs were available to take to get rid of this thing? The more I read on the internet the more questions I had about ALS. The information, or maybe I should say the lack of information, was very confusing.

When I started researching treatments, I came up with nothing. I spoke with our good friend Anne Marie Lentz and she joined the search on the internet for hope. A few days later she and I had come up with the same information, that a Dr. Bradley at the University Of Miami Neurology Center was a researcher and expert on ALS.

Now before I go any further let me say that the doctor who originally diagnosed Diane also told her she should have a second opinion, and that his office would get in touch with her to set up an appointment with his mentor, a doctor at Shands Hospital in Gainesville. Well, we waited and waited for them to call. Diane made repeated calls to this office trying to get information on the appointment. We waited for someone to call us back. Finally, one week after the diagnosis I called the doctor's office very upset. I told the receptionist that I wanted someone to call us back immediately with the appointment information; I said that you can't just give someone a death sentence and send them on their way. About 20 minutes later the Doctor (who will go nameless) called me and apologized for the delay. He said he would personally see to it that the appointment was scheduled immediately. Well, we're still waiting for that call. We never received any communication; not a phone call, an email or a letter. Yes, I'm still upset over this. How can anyone do this to a family? Shouldn't these doctors be held accountable for this lack of follow up?

Anyway, Anne Marie and I both found references to this Dr. Bradley in Miami. I researched him and found an email address for the study coordinator for him at the time, a Ms. Julie Steele. I emailed her and asked for her help. What could I do for my wife? Who knows how to fix ALS? She responded via email right away and became my sounding board in the early going. I will forever be indebted to Julie for her compassionate responses. After several emails, Julie called me and we talked for a good while. She was straightforward and answered my questions without omission of facts and didn't try to sugarcoat the disease. She recommended Diane and I set up an appointment and have Dr. Bradley or Dr. Verma test Diane and give another opinion. This we did. Her appointment was set up approximately one week before Christmas 2002.

In the meantime, Diane and I decided not tell Amanda anything until we had the second diagnosis. However, Diane did ask her parents to visit so we could tell them and make them aware of the gravity of the disease. Even after their visit, I don't think they quite understood what was to come, especially when Diane's progression accelerated.

A week before Christmas, Diane, Amanda and I left for Miami. We dropped Amanda off at her grandparent's house and made our appointment with Dr. Verma at the University of Miami Neurology Center.

The lobby was filled with patients suffering from many kinds of neurological impairments. It was very depressing. Julie Steele met us in the lobby. She was a young thirty year old with a vibrant smile and positive attitude. As best she could, she made us feel at ease in a very uneasy environment. She talked with us about the disease,

Dr. Bradley and possible studies we might get involved in if indeed Dr. Verma agreed Diane had ALS. She also advised us on joining the MDA clinic at the University of Miami. They fund some ALS research and they have a lot of ties to the ALS community.

Once we were in Dr. Verma's office he proceeded to test Diane with simple reflex tests and reviewed her MRI and EMG test results. By this time, approximately six weeks after the initial diagnosis, Diane and I were pretty resigned that "yes" indeed she had ALS. It was the only thing that made any sense. So when a serious looking Dr. Verma pushed away from his desk in his desk chair with wheels across the office floor and held both our hands and then said "Diane and Keith I'm sorry to tell you that in my opinion you Diane have ALS" we both jumped. We thought he wanted to pray or something. It was one of those "funny" moments that you had to be there to really appreciate.

Dr. Verma was very nice and explained the disease and told us to live our lives as normal as we could. He said he would not discourage us from any "holistic" forms of treatment unless they were proven to do more harm than good. He was very forthcoming for a doctor. We understood that he understood what we were in for.

We picked up Amanda and started driving back to Orlando. This is when we told Amanda what exactly was wrong with Diane. Diane was very up front with Amanda and tried to explain the disease but downplayed what could be the final outcome. Amanda took the news just as we had; she was in a state of shock. But I don't think at this age she was able to grasp the implications of what she had just been told. Heck, Diane and I couldn't understand the implications of what we knew.

During the Christmas holidays Amanda and I went to an Orlando Magic Basketball game. On the way home Amanda, out of the blue, asks me "Can mom die from this ALS disease?" I told her "yes". She broke down and cried. We both cried. She was scared. I was scared. Diane was scared. How could Amanda live without mom? Amanda and Diane were incredibly close. Each one was part of the other. For Amanda to imagine not having Diane there for her was quite frightening.

Even though Diane and I both knew the road was going to be rocky we didn't fully grasp this disease until we experienced each progression or crisis. So, we lived our lives the best we could. During the holidays of 2002 we made our first of many purchases for equipment. By this time Diane needed an LFO. This was a plastic insert that looked like a shoe horn that fit in the shoe and made sure her left foot wouldn't drop down. Dr Verma had written a prescription for this device. On our way to a specialist to get fitted for the LFO we decided to stop at a medical supply store. We asked about the LFO and they showed us one for \$50.00. We then left and went to the specialist who then quoted us \$700 for the exact same device. Here was another experience with the medical community that is so out of control with costs incredibly high and customer service being very sloppy. We left the Specialist's office and bought the \$50 LFO from the medical supply folks. Our Health Insurance wouldn't cover this device. We also needed a cane for Diane. I never got use to seeing her with a cane. It made her look so very old and disabled. I kept thinking about the beautiful and talented singer and dancer who had been on stage with me for so many years. Now here she was walking with a cane; eventually she needed two canes to get around.

On February 1, 2003, the day the space shuttle blew up, Amanda got a call from the Dragon Tales people asking her to please re-join the cast in Oklahoma City. It seems the night before they had to fire the little girl that had taken Amanda's place. Actually, they dismissed the Mother of the little girl for reasons we never were privy to. So Diane and Amanda get on an airplane six months after coming off the road and now go back on the tour. Amanda arrived late Saturday night then did a show on Sunday. The next day they flew to Denver for a week of shows and then on to Phoenix for a week of shows and Amanda trained the replacement. Diane stayed in the hotel room most

the time because she couldn't walk from the venue to the hotel and back. She was quite upset at this. It tired her and frustrated her. They arrived back on a Sunday night just in time for Amanda to start "Music Man" at a local Orlando Dinner Theatre called the Mark II.

In the Spring of 2003, Diane and I purchased a big ole' 2003 Ford Crown Victoria car. We were told we needed a vehicle that could accommodate a Class III hitch in order to hold the lift system which held an electric scooter. Total out of pocket expense for the scooter, the lift and hitch ran about \$3500. Diane and I had medical insurance but every turn we made they denied coverage on most medical expenses, including some second opinion testing and the scooter system. This started a downward trend in our finances. We had leveraged the house to help finance the TV show but now these funds were being diverted to pay for medical expenses. The debt continued to grow as Diane's needs changed.

In April of 2003, Amanda was performing at a local dinner theatre. She needed to be picked up around 10:45pm at night. The theatre was a good 45 minutes away from our home. I was working upstairs in my office that is over our 4 car garage. Diane yelled up to tell me she was leaving to go pick up Amanda. I said goodbye and went back to my editing. Now when you edit video you become totally focused and you tend to shut the world out, which was the case this particular night. Every once in a while, though, I thought I heard a whistle outside. At first I thought it was the TV, and I ignored it. About 30 minutes after Diane left I realized that the whistle was coming from outside. Now we live on 5.5 acres in the middle of nowhere, so when you hear strange noises you take note and investigate. I went down stairs and in to the garage and there I see the Crown Vic sitting there. I'm totally surprised because I'm thinking Diane was long gone, I yelled "Diane" and she responds with a "thank God you're here". She had fallen when giving our dogs water over in the far corner of the garage, and she couldn't get up. She had reached for everything she could find to help her up but to no avail. She sat on that garage floor for all that time whistling trying to get my attention. I ran to her and lifted her up in to my arms. She held on to me very tight and started crying and said "I hate this. I hate this disease". This was the only time in the entire time she had ALS that Diane ever broke down and complained in front of me. And this was two years before she died and was when she was still quite mobile and self sufficient.

To my dying day I'll never comprehend the kind of strength she had while combating this disease. She always maintained an attitude that the glass was half full. She laughed and consoled the very people who were there to cheer her up. Remarkable is an understatement when describing Diane.

By this time, May 2003 Diane's right leg was growing weaker and her left leg was almost useless. ALS is strange in that even though you lose the ability to move a limb you can still "feel" like normal. Diane fell a lot. She was hurting herself everyday. It became apparent that in a short while she would be a total paraplegic.

One major fall took place in the bathroom of Amanda's dance studio. Amanda was helping her mom to the toilet when they both went down. Diane's foot bent the wrong way and she was in major pain. A good friend of mine happened to be at my house when I got the call so he and I rushed over and took Diane and Amanda to an emergency care facility. They X-rayed the foot and determined she broke her toe. Since nothing can be done about a broken toe she just had to endure. A short while after this fall Diane ran in to a wall with the scooter and broke the other toes on the other foot.

This time period was probably the most dangerous to Diane's body. As the disease progressed, she lost her sense of balance and her injuries piled up. Everyday brought more bruises and cuts.

The most dangerous part of her day became showering. We have a dedicated shower stall in our bathroom with a 4

inch high threshold going in that drops 8 inches to the shower floor. As Diane's loss of leg strength increased, the simple task of "taking a shower" became increasingly perilous. At first she would enter the shower very gingerly and was very aware of her lack of stability. Then she asked me to install a bar so she could hold on to it while showering. During this stage I would shower with her so I could help her in and out of the shower as well as hold her and wash her. This period of time didn't last long and very quickly became seriously dangerous for both of us. Several times she started falling either going in or out or just standing in the shower. Both of us went down several times. As was our way we laughed and joked about the circumstances we found ourselves in, but inside we both were scared to death.

Diane and I discussed and even brought in contractors to give us quotes on remodeling the bathroom so it would make showering and using the toilet easier for Diane. We never did make any major changes, thank goodness. If we had, the change made would have only been useful for a short time. Her fast progression made her bathroom needs change almost on a daily basis.

Diane was extremely headstrong about everything she did. She wasn't ready to accept certain aspects of this disease. She was going to fight the effects of her limited abilities to the very end. Hence, when I suggested a bench for the shower she fought the idea. Honestly, I think the main reason she finally agreed to the shower bench was more out of concern for my safety than hers. I hurt myself plenty of times trying to keep her safe.

Excluding the safety aspect of showering with Diane, I have very fond memories of these times. We talked, we kissed, we laughed and we groped a little. I loved her so much and to see her losing her ability to stand because of this disease was so disheartening. But I found myself falling in love with her all over again. She was a remarkable lady with enduring strength. To talk to Diane you wouldn't think she was a brilliant intellectual being. She wasn't "book smart" but she was "street smart". Moreover, she was wise.

The shower bench was helpful. It allowed her to have some privacy now while showering. I'd help her on the bench, and then the seat would slide in to the shower. The door opening to the shower was very narrow so I had to lift her legs and feet to get her totally in the shower. I had installed a disconnected shower head so she could put the spray wherever she needed. This worked quite well except for the water splashing on to the bathroom floor. But at this point we really didn't care. She had restored a measure of independence to her life. This was extremely important to her.

On September 5, 2003 Diane threw a surprise birthday party for me at a local Italian restaurant. She got me really good. I had no idea. I thought it was just a dinner with Joe and Tina Calderone, close friends whose wedding we'd performed at many years before. Joe is also our family dentist. Diane was always throwing surprise birthday parties for me. Each time she'd get me. For as many as she had thrown over the years you would have thought I'd be expecting them, but I never did. This one was very special. I met her and the other couple there and then we walked to a back room where 20 of our closest friends yelled surprise. It was great. My dad and stepmother were there and it was a great feeling to share this night with these folks. Life with this disease was getting harder each day and this was a great break from the hardship. A few minutes after the initial surprise my brother and sister in law walked in, surprising me all over again. Larry and Shirley LaMotte had come south from Baltimore to spend a few days with us. Over the next two years they made the trip many times. They knew Diane's days were numbered and I needed the emotional support, especially from my big brother. There aren't words that can articulate how much these trips meant to me and Diane. .

I remember that when we got back that night, Larry and Shirley said Diane's driving was a bit erratic. They questioned me as to whether she should still be driving. I told them what Diane had said to me, that when she felt

she was a danger to herself or someone else she would stop driving. That decision came about a month and a half later.

Diane had had an appointment with the family doctor in Oviedo and she later told me that she almost fell while trying to walk to the back of the car to lower the scooter and get on. She made it but it was tough. But even worse was when she had to get back in the car after the appointment. She said she barely made it to the car and close the door to drive home. This really shook her up. She made the decision shortly after that to stop driving.

This was also around the time that Amanda was getting her learners permit to drive. The day of the test was October 6, 2003 and I took Amanda to get her permit. We were starting to get in the car to come home when Diane pulls up next to us with that big smile on her face. She didn't want to miss seeing Amanda drive for the first time. This was vintage Diane. The problem was Amanda was too scared to drive. So we all went to a Denny's for lunch. After lunch I was able to talk Amanda into driving while Diane followed in the car. She was so proud and I believe even happier because she was able to share this moment in Amanda's life. Diane had driven Amanda to dance rehearsals, auditions, vocal lessons and performances for 15 years, now the roles were about to change.

Now when a principal driver in a family no longer can drive your entire family life gets totally discombobulated. Now it meant I had to run Amanda to her dance classes, to school each morning and afternoon, pick up the groceries, and run Diane here and there. To say it became stressful is an understatement. How does one run a business when a good portion of your day is dedicated to personal family needs?

Not being able to drive anymore had to be devastating to Diane. Her freedom to get up and go was now gone. But like typical Diane, she didn't let on that it bothered her and took the change in stride. Now Amanda became the chauffeur, and because an adult driver had to be present in the vehicle, Diane was always the passenger. They went everywhere together and Diane was still able to do what she cherished most, and that was watching Amanda dance, act, sing and enjoy life's experiences. Amanda was Diane's life.

Also, around this time our household experienced the first of many medical crises. It was December 2003 around 11:30 at night and I was in my office editing video when the business line rang. I ignored it but for the next twenty minutes or so the phone kept ringing. Finally, Amanda gets on the intercom and yells for me to get downstairs quick that something is wrong with mom. I rush downstairs and there is Diane in the wheelchair facing the toilet area. Her face is white as snow, her features are distorted and she's unresponsive. I'm thinking she's having a stroke. Then she came to and muttered something about lifting her feet. Then she contorts, makes an awful noise and slumps low in the chair. At the same time she loses all bodily fluids. To say everything was a mess would be an understatement. The phone was in her hand so I grabbed it and called 911. I lifted her feet and legs and propped them up on a laundry basket that was close by.

Slowly, she started to be able to communicate. Even though we live in the middle of nowhere, the fire station is outside the sub division's back entrance, and the paramedics were there in about 2 minutes. They took her vitals and said she needed to be transported to the emergency room. She said fine but wanted me to get her cleaned up before they put her on the stretcher. So for ten minutes she's brushing her teeth and hair and letting me wash her before she declares she's ready. So I wheel her out to the living room where the paramedics help her on to the stretcher and then move her to the largest ambulance I have ever seen. Where the stretcher needed to be slid inside had to be about four feet off the ground.

Wouldn't you know it but it starts to pour. The Paramedics place a blanket over her, and four paramedics and fire-

men start to hoist her up and in to the ambulance. As they do, one of the Paramedics nearly drops her backwards. I'm standing there in shock, not believing what I'm witnessing. Somehow they caught the stretcher, and in Diane went.

We spent the night in the emergency room. I called her Mayo Clinic doctor in Jacksonville and woke him up and told him what was happening. He said he believed it was something called "Vaso-Vagal Syncope." It seems Diane had been lying in bed watching TV. She needed to go to the bathroom so she got out of bed and into the wheelchair and pushed her way to the toilet. But since her legs were basically paralyzed, her blood had pooled in her lower legs. It's similar to when you get up fast and feel lightheaded. As she got to the bathroom she'd start passing out and then after a moment would come to. She picked up the phone on the bathroom wall and dialed the business line hoping I'd pick up. She would then pass out again. Then she'd come to and hit redial to call me. Meanwhile, Amanda was asleep in her room. She is usually a very sound sleeper but for whatever reason the ringing phone woke her up, and she went in to our room and found Diane. Thank goodness she did. I'd hate to think what might have happened if she hadn't.

As I said, they kept Diane overnight and confirmed what the Jacksonville Doctor said and released her. Amanda had exams this day and because she was up all night she missed the early exam but after a few hours of sleep decided to try the noon exam. Well, forty five minutes after bringing Diane home and forty five minutes before the start of the exam and five minutes before I am to take Amanda to school, a major storm hits and drops a big ole' pine tree directly across the driveway. We couldn't believe it. What else was going to happen? I think this was just a pre-cursor to what we were in for in the next few months. I got out the chain saw and Amanda and I cleared enough room for us to get the car out and she made it in time for the exam.

It was at this point that Diane and I started really talking about the future. At first, we couldn't discuss anything to do about death. It was just plain impossible. But as the realities of ALS started to creep up we had to. Many decisions were made and many clarifications about DNR (Do Not Resuscitate) issues were discussed. We talked about to be vented or not to be vented. From the very beginning Diane said "absolutely not". She would not live on an artificial anything. To this day I don't know how she was able to make those decisions so far ahead of when they ultimately needed to be made.

Because of the potential violence in an ALS death (choking, heart attack and suffocation) I needed to know what decisions Diane wanted me to make. I asked the medical people constantly about what might happen and how Diane and I might handle that particular situation. I was simply scared to death an "event" would happen and I'd have to make the decision as to whether Diane lived or died. This remained on my mind to the very end and it is something I still contemplate even today.

One of the issues we discussed was what would happen to Amanda if something happened to me. Diane and I both agreed that there really wasn't anyone on either side of the families that were in the position to finish raising her. By this time she was 15 years of age (going on 30). Amanda was always more mature and worldly than most kids her age, and some adults as well, but she was still a kid and needed guidance. Financially, she would be okay. I knew that my brother could manage her money till she came of age, but who could encourage her to fulfill her dreams? Diane and I both realized there was only one person who knew Amanda and loved her almost as much as we did; her drama teacher and long-time family friend, Janine Papin. Janine was a single mom and had raised four amazing kids by herself. She knew Amanda and she knew what it would take to guide a free-spirit, super talented, singer/dancer/actress.

We invited Janine over to the house and asked her if she would agree to raise Amanda in case both of us departed

this world. Literally, we didn't even have the entire question out of our mouths and she said "yes of course". She gave us the go ahead to put that clause in to our will. This took a great deal of worry off Diane and my minds. We knew Amanda would be fine in case something happened to both of us.

In January of 2003, Julie Steele from The University of Miami got Diane enrolled in a clinical double blind study using the Arthritis drug "Celebrex" in ALS Treatment. It was a very aggressive treatment with the ALS patient receiving approximately eight times the normal daily dosage of Celebrex. After 10 days Diane broke out in a major reaction to the sulfonamides. I called Julie and she said to stop taking the drug immediately as it could cause a condition called "Stephen Johnson's Disease". I read up on this and couldn't believe what I read. Basically, among other reactions, it causes your skin to fall off.

Diane stopped the treatment and after a few days was back to normal. However, this was a very depressing time. There is no known treatment for ALS. The patient gets the diagnosis and that's it. You are on your own. No hope. No drug. No anything. There really is no reason to even see a doctor because all he can tell you is what you already know and that you are losing the ability to move and breathe. So, when the Celebrex study came out we were hopeful. At least we were being given a chance to fight this disease. Diane and I were fully aware that this trial was experimental but we thought "heck, who knows, we may just get lucky." A couple of years later the results of this Celebrex trial showed no improvements to ALS patients at all.

A few months after the Celebrex study Julie suggested getting involved with the IGF-1 study, which was being conducted countrywide. The local resource was located with Dr. Kevin Boylan at the Mayo Clinic in Jacksonville. This study was getting high hopes from all the leading researchers. They had infected lab rats with ALS, and then once paralyzed given them treatments with this IGF-1 drug. After several weeks, 80% of their movement was restored. These results were incredible and extremely promising. The researchers now had permission to start human trials. The qualifications were strict and Diane just made the time requirements. She had to have been diagnosed within 6 months of the application date. However, after spending an entire day getting re-tested (at our expense) they denied her from the trial because of a slightly elevated result in a liver test. We couldn't believe it. First, we were shocked and stunned and felt like the world was caving in on us all over again. Then we got mad. I was determined to get her into the study. We needed some way to fight this disease. Just because one of the many test results was elevated, they couldn't deny us a chance to save Diane's life. It was after five pm when we were told "no" so we had to fight the system starting the next day. Diane was off on an errand so I called the doctor directly. He explained why she was being denied the clinical trial because of this test result. I said she had just had her liver tested a week before by the family doctor and it tested fine. He said his test was more in depth. I felt like we were splitting hairs. I kept pushing him looking for a way around this. We discussed the medications Diane was currently taking. I read him the names of each drug and he said that one of them could easily raise this particular result of the liver. He said he would consult with the research staff to see if this test result could be exempt and get back to me immediately. The next day Diane was in the study.

All this testing had a serious economic impact on our family finances. The clinical trial researchers didn't pay for any of the tests required for her admittance to the study, and they required still another diagnosis by the Mayo clinic team. We had to pay for this even though she had already had two prior confirmations of the ALS diagnosis. Each test cost in the thousands. Slowly, or rather quite fast, Diane and I were sinking in debt. Keep in mind during this entire time we were still going forward with the new business venture, the TV show. Business and medical costs were escalating at an enormous rate, and I'm doing my best to keep this from Diane. Even so, she knew we were under a tremendous financial strain. Literally tens of thousands of our personal money was flying out the door.

The IGF-1 clinical trial required two injections every day in the stomach. They were quite painful but Diane learned to do it in stride. I couldn't administer them. Later on I would do things to help Diane that I never thought I could do, but at the time these injections made me feel squeamish. Actually, now I know I could have done it but only after the total experience that I've gone through do I realize it. At the time I was a "wimp".

We had to keep the bottles of the drug refrigerated and Diane had to keep a log of the times she gave herself the injections, as well as when and whether she ate before or after the shots. Recording these details was a pain, but you do what you have to do when it is a matter of life and death.

In December 2003, Diane was accepted to receive Medicare and Social Security benefits. Normally, this is a two year plus process but because of a 1999 Congressional bill, anyone diagnosed with ALS receives immediate benefits. The reason ALS patients get such fast approval is that most ALS patients don't survive two years after their diagnosis and the need for funds is immediate for their care. I'm proud to say that as a former resident of the State of Maryland my Senator Paul Sarbanes introduced that bill. He is also a personal friend of my brother Larry. Larry has relayed my heartfelt appreciation for his hard work in making this bill a reality. To date ALS is the only disease that has this quick action element for benefits.

Medicare status also brings the ability to have hospice care. Medicare pays all costs and the patient and family get true guidance and superb medical care. At least we did from the "Hospice of the Comforter" in Altamonte Springs, Florida. The impact they had on how we fought this disease and our mental health is entirely beyond description. So on June tenth of 2004, we became a hospice family. They provided equipment and drugs and moral support. They answered our many questions as best they could do and brought laughter and strength to our household. The hospice folks are a special compassionate group of people.

Prior to Hospice, however, we struggled each day. Where do we turn for treatment or guidance or money or advice? It was so frustrating. Diane remained strong and upbeat and led Amanda and I along. I counted on her during these days because I was totally at a loss for what to do for her. Somehow she always knew what to do next and prodded me along.

We attended a local ALS support group and met some couples who were dealing with ALS at different stages. Diane was actually one of the healthier ALS victims of the bunch at the time. She could talk, breathe fairly normal and her upper extremities worked fine. Most of the others were simply too disabled to contribute much to the group.

This group of ALS families and patients were always laughing and at the same time crying. Each month we'd attend a meeting only to find another one of the ALS patients had passed away. And each time we'd all shake our heads and try to get rid of the thought that one day it would be our loved one who had passed.

As Diane's disease progressed we continued to attend these meetings. However, the group started to be made up of new families and the original group of ALS patients were gone, having all passed away. This new group was extremely negative and each meeting seemed to be a "bitch" session for some wives to complain about their bitter husbands. It was the same each meeting, month after month. Sometime in the spring of 2005 Diane told me she didn't want to attend these meetings anymore as they only depressed her. I agreed with her since I felt the same way.

In January 2004 my ex-wife Terrie came for a visit. Diane and Terrie had been very close friends while I was still married to Terrie and on the road. They remained friends and talked often over the next 20 or so years. We had a

great weekend. It was like old times with both of them laughing and doing what they enjoyed most, making fun of me. Amanda wasn't quite sure about all of this, but with Diane and I she was used to the unorthodox.

Diane tried very hard not to acknowledge the ALS this weekend even though she was in the wheelchair. However, during dinner the second night she had a major bodily function accident. I got her to the bedroom, cleaned her up and put her to bed. She and Terrie talked for quite a while by themselves. I knew that the last thing in the world she wanted Terrie to see was her loss of control and just how bad she was. Terrie left on Sunday and that was the last she ever saw Diane alive. She called from her home in North Carolina just about every day checking up on Diane, Amanda and especially me. To this day, I don't know what I would have done without those daily conversations with Terrie. Other than Diane she was the only person on earth that could have gotten me through this nightmare on a daily basis. I know it took a lot out of Terrie as well as me. I truly believe every caregiver needs someone who is there for them. I'll always be grateful to Terrie for being there for me.

Being a caregiver to an ALS patient has got to be the hardest thing on this earth to experience. You have to watch your loved one die a little each day. You feel absolutely useless because there is no treatment or drug to give you hope. By the time the loved one passes you have died with them. You have nothing more to give. Unless you've experienced this I believe you can't know what I am talking about. I had a beautiful lovely wife and together we had a terrific relationship and marriage. To this day a large part of me is dead and will probably remain that way forever.

Late February 2004 my dad and stepmother took Diane and me on a 10 day western Caribbean cruise. Diane loved it; it was her first and only cruise. Even though most of the ports of call she couldn't really experience to the maximum, she was still the life of the party. I was however able to get a cab and get her to the Panama Canal. I have video of her sitting in her wheel chair just 10 feet from the largest tanker ship I've ever seen, going through the locks of the canal. She looked so very small in that chair as I looked down from the observation tower high above. I got all choked up, here was my once energetic beautiful friend and lover reduced to a chair. Yet even in this state she radiated hope and love. She was smiling and laughing and being Diane.

Most nights aboard ship we ate dinner with my dad, Bettie and other friends in the main dining room, but on two separate nights Diane wanted to hit the sushi bar and have a quiet dinner, just the two of us. She loved sushi and could put it away. We started each of these two nights with some wine and a quiet dinner. But both nights in the middle of dinner, bam. She had an accident. She was humiliated. I got her out of there and back to our handicapped room. I literally had to shower her down to clean her up. Actually, I was quite upset with her, before the trip I begged her to wear adult diapers just in case of times like this. The accidents were happening on a more frequent basis now. She refused and wouldn't even listen to me. I got frustrated with her at times like this and was not very cordial to her sometimes. Recently, my daughter Amanda reminded me of these little "fits" I would throw when I'd be in the middle of some issue with business and I'd have to stop and clean up Diane. I'd lose my temper with Diane occasionally. I was so frustrated with the situation and I would take it out on her sometimes. Mainly, this occurred in the beginning of when she required full time care. As time went on and she progressed I learned to be more patient and understanding. Eventually, I matured enough in the care giving role that I know longer became agitated with the interruption.

I told her I was going to take them on the ship and she said if I packed them only I was going to wear them. I told her I would if she would. Still she wouldn't. She was determined to be independent as long as possible. She was going to fight this loss of control till she couldn't anymore. Well, that came about two weeks after the cruise. She just out of the blue one day said okay lets use the diapers. After that life was actually a bit easier. No more taking her in to the ladies rooms in restaurants. No more accidents in the mall. No more leaving the dinner table with

company in the middle of dinner.

As she lost the total use of her legs that meant lifting her in and out of the chair and on to the toilet or in to bed or in to a chair. Or transferring her into the car or on to a chair in a restaurant. It was constant lifting on my part. After several months of this, my back was shot. I couldn't work anymore without excruciating pain. I kept asking people at the ALS support group if they knew of solutions to this issue. They recommended a "Hoyer Lift". I checked it out but found it to be cumbersome and not very efficient. Then one day in the spring of 2004 I got a call from the director of the ALS association here in Florida asking if I might need some kind of lift system. A lady in Cocoa Beach was giving it away, and did I want to check it out? I said "okay" so Diane and I took a road trip to Cocoa. It was fantastic. The system was battery operated and there was no lifting and/or turning to transfer the patient (more on the details of the system later). It was a self standing system that was extremely expensive but she was giving it to us for free. Actually, she had two complete systems for us. We put one over the bed and the other I modified to fit over the sunken bath tub. Now Diane could take a Jacuzzi bath, something she did until two days before she passed away.

I can't tell you how wonderful a thing it is that this lady did for us by giving us that lift system. It made the quality of our life so much better and eliminated some of the stress. I'll always be indebted to her for that wonderful gift.

As I wrote earlier, Diane researched, applied and received approval for Hospice care on June 10, 2004 from the Hospice of the Comforter. This is a non profit Hospice care facility based in Altamonte Springs, Florida. Now from what I have learned, a FOR profit and a NON profit Hospice care organization treat their patients very differently. The first noticeable difference from what I hear is the FOR profit has two to three times the case load of a NON profit facility. It doesn't take a rocket scientist to figure out you will receive more individualized care from a medical organization that is not so pressed for time. Hospice of the Comforter's medical staff never rushed us or made us feel uncomfortable.

The second issue I hear is the employee turnover rate of the FOR profit Hospice. Again, you don't have to be too smart to understand that you'll get much better care from a stable, reliable medical staff. The Hospice of the Comforter staff was always friendly, upbeat and reliable. For all the bad luck we had suffered, the one piece of great luck was having "hooked up" with this Hospice. At the time we signed on with them, Diane was experiencing some shortness of breath, burning pain in her joints (especially in her legs at night while in bed). She was a paraplegic, and although mentally she was strong, she was frustrated at her physical situation.

Her frustration was something she took pains to conceal from me and Amanda. Only after a year or so after her death did I learn from Hospice folks and some close friends that Diane expressed anger during some of their visits. It was so like Diane, to protect us, even though she was hurting. This she always did. Simply put, it's what she did always.

It took about six weeks to get Diane's hot stabbing and burning pain under control. Hospice kept trying different combinations of drugs until they hit on the right amounts to manage Diane's pain and sleeping issues.

Summer 2004 came and went with the disease progressing. I was able to get Diane in to the swimming pool for the last time that summer. We propped floats under her and around her; she was so excited and happy to be floating and not to need to use her muscles. She eventually fell asleep for about a half hour in the pool. I remember just watching her there in the pool and remembering all the wonderful times the three of us had in the pool and especially the Jacuzzi. Diane was known for serving us dinner in the spa. It was one of our favorite family activi-

ties and we did it often. On the occasion of these “dinner in the Spa” evenings, Amanda would perform for us. She’d make believe she was the spokesperson for the builders of the swimming pool and do a “mock” commercial complete with voice over and “action” when she would say her line then dive in to the pool.

Diane and I loved these times. We’d hold hands and kiss as we watched Amanda swim and play. Little did we know that these times would soon be a memory.

In writing this book I have found that my time sequences are a little out of order. I never kept a journal during this ordeal. Now I wish I had. I didn’t know I would be putting my memories and thoughts to paper. So, I believe it was late spring or early summer 2004 when, toward the end of dinner one night, when Amanda had since left the table, Diane maneuvered her wheel chair next to me and put her left arm on mine. She said “It’s hitting me in my left arm, I’m losing the strength.”

I just looked at her. It felt like we had just got the news of her having ALS all over again. This meant the ALS was traveling up her body and was now developing in to what is known as “Bulbar ALS”.

I’m sure she had known this for a while and she finally had to tell me as she knew what impact it would have in the upcoming year. I believe at that moment she truly knew her days were numbered. I can look back now and realize some of the things she commented on or decisions she made which were a result of that night. She knew that the ALS was poised to hit her lungs and throat. And that would be it.

We began to have serious discussions about how she wanted to die and about Amanda after she was gone. As time went on we were able to talk about issues quite easily, but not at first. Usually, it was I who couldn’t accept or deal with her not being here. She remained Diane. She was incredibly strong and very rarely showed any sign of being scared or bitter. How she did this I have no idea and I am in awe, even now, of her.

How do you face your own impending death and still be able to comfort others? Diane was truly amazing. I always knew this but seeing her handle all she had to endure and still care about others first was totally incredible. I was blessed to have known her and be loved by her.

The summer of 2004 was a summer like no other, the likes of which I hope I never experience again. Of course I am talking about the three hurricanes, Charlie, Francis and Jean. Like most Central Floridians, we spent the Friday that Hurricane Charley hit waiting. The skies grew increasingly dark and around 9pm the full force of the storm was upon us. As the track would later show, the “eye” traveled about 5 to 10 miles away from our house. That means that the most powerful part of the Hurricane was right at our doorstep. It was scary but at about midnight the winds started to subside and we realized the worse was over.

Since we have a business phone system which only works on electricity, we lost our main phones early on. The only two phones that worked were land lines in Amanda’s room and Diane’s and my bathroom. At around midnight Amanda went to use the phone in her room to call someone while I went up to my office on the second floor to check on things. Diane remained in the kitchen in her wheelchair. I returned about 10 minutes later to find Amanda trying to calm her Mom down and to breathe. Amanda couldn’t say what was wrong. After a few minutes Diane calmed down and said she felt very helpless, she started panicking again, which in turn caused her to have difficulty breathing and then start choking. As time went on, however, she seemed to get better.

I walked out the back door and looked Southwest toward Orlando and I realized there was something terribly different with the skyline. Actually, what it was was that I could see a skyline. Normally, all I’d be able to see were big tall pine trees. Because it was dark I couldn’t put my finger on what was making everything look so weird to

me. I found out the next morning.

We went to bed a short time after 1am and had candles lighting the way and all around the master bedroom. I used the lift system to get Diane to bed. Thank goodness the lift system worked off batteries. Since we always lose power out here in the woods I knew the lift system had to be fully charged, because who knew how long it would be before we'd get power restored after the hurricane. But who would have thought it would be nine days?

Around 4am Diane tells me she doesn't feel well and to get her to the bathroom as fast as I can. Well, let me tell you that while the lift system is a remarkable apparatus, it is not the fastest way to transfer someone. Many ALS patients die from choking on their own saliva, or as we were about to discover, their own vomit. I got Diane to the toilet where she proceeded to be sick. Now understand at this time Diane had pretty much lost her ability to sit up. And as I hold her up on the toilet, I realize that the vomit is staying in her throat and mouth; she doesn't have the ability to expel the contents. She starts choking, and is struggling to breathe. I "rocked" her forward to help her get rid of the vomit, and then would straighten her back up. I needed to keep her upright because she had lost the ability to breathe when she was leaning forward.

Midway through the crisis I was pretty sure Diane was going to leave us this night. She was exhausted and helpless. I figured she would die and I'd lay her on the bathroom floor till I could somehow get word to someone to come get her. All I could think of was that I needed to keep Amanda from seeing her mother this way. I kept reaching into her mouth to clear her airways and then leaning her back and forth using gravity to assist me. She was white as could be and was semi-conscious.

It's funny the things that run through you mind in times like this, but all I could think about was keeping Amanda out of that room. Maybe that thought is what propelled me to keep insisting on Diane coming back to me. After about twenty minutes or so she started breathing better and color started coming back in her face. Neither of us said a word for the longest time. After a while I told her I wanted to get her back in bed and did she think she could make it. She shook her head "yes". So, I lifted her back in the chair and used the lift to get her back in bed.

I shifted more candles around her so I could see her face better and just stared at her watching for any sign of trouble. She hadn't said a word for the longest time and then out of the blue she says "I don't ever want to go through that again." That's all that was ever said. She was quite shook up. Looking back I believe she realized that night what could be in store for her at the end. I believe she made some decisions about how she wanted the end of her life to go based on events of that night.

Most people in Central Florida felt their life had been devastated by Hurricane Charlie, Amanda and I were just trying to keep Diane comfortable. Around 7am I wheeled Diane out to the garage and opened the doors to see what daylight would reveal. When I lifted the garage doors our hearts climbed in to our throats. There were literally hundreds of trees down surrounding our house and across the driveway. The beautiful "state park" forest of tall pines and oaks was gone. Except for a couple dozen trees broken in half no trees were standing, it looked like we were bombed. We couldn't believe our eyes. We'd lived here twelve years and always admired and felt so very proud to live in a piece of paradise called "Seminole Woods". Now it was all gone.

I cleared a way for Diane and we went partially down our driveway to the first downed tree. I'm looking at the damage when I hear Diane choking again. I turn around and see her doing a repeat of the 4am episode. Fortunately, this only lasted a couple of minutes but nevertheless, it reminded me of what needed to be done immediately. That was to find a way out of here. Once Diane was squared away, I got Amanda and my chainsaw and we started cutting trees that were across the drive. We couldn't really see or get to the road because of all the debris. I was a

man possessed. I needed to clear a path for a car to get out and or an ambulance to get in. I realized then that even a helicopter couldn't land anywhere near us because of the hundreds of downed trees.

When the hurricane hit, we had a young woman named Heather spending a few days with us. Heather had been Amanda's wrangler (a wrangler is someone who supervises underage performers back stage) and dresser during the Dragon Tales tour. I told Heather to keep an eye on Diane while Amanda and I cut wood. That's exactly what I did for the next 3 months and here it is a couple years later and I'm still cutting wood.

Anyway, by around noon Amanda and I had cut a path to the road. However, at the end of the drive the power lines were dangling across the driveway access. This was quite dangerous if the power was still on. We started cutting a path on our street and then the next street that was our way out of Seminole Woods. We were joined by our neighbors who had more chainsaws and tractors. Around 2 pm we made it about 600 feet to the closest main road out of Seminole Woods. This was a dirt road but that day, it looked to me like a road made of diamonds. Just then, some guys with huge excavation equipment came rolling up that dirt road and said the road was clear to the closest county road. At this point I knew we could get out and or get an ambulance in. I started to relax a little.

I went back to the house and could see Diane was still having trouble breathing. Major phlegm was blocking her airway and she didn't have the ability to expel it. She was very distressed. We tried everything to help her but in the end the only thing that seemed to work was me putting repeated pressure to her diaphragm as she tried to cough up the phlegm. We did this for an hour. It worked and really we never had that issue again in her illness. And as always, Diane and I worked together to solve this problem. This is what we always did in our personal life and our professional life. We tackled issues head on, not always agreeing on what needed to be done but in the end working together to find a solution or compromise.

The reality of our situation was sinking in fast; we were without electricity with a paraplegic in a wheelchair who was having breathing problems. The situation was dire. I needed a generator to charge Diane's powered wheelchair and the lift system, as well as all other necessities. So around 3:30pm I drove 3 hours to West Palm Beach and met my sister in law who gave me a power generator courtesy of Diane's Mom and Dad who lived in Miami. I got back to the house around 11 pm that night.

The next week and a half were horrible and some of the toughest times in my life. It was the beginning of an emotional and physical downturn for me. I spent all day cutting trees and hauling them by hand to the side street for FEMA to take away. My chainsaw was not in the best shape so it made work even harder. I had some help but mostly I did all the work. It was extremely hot. Most days the temperature was 95 degrees or better. On top of this I couldn't run my business. My video business and TV show requires electricity. I repeated the same show for a couple of weeks, although because the TV station was off the air thanks to the hurricane, it didn't really matter early on.

My day started around 7 am, when I tried to get as much work in before the sun zapped all my energy. However, I always had to stop and take care of Diane's needs. Since she was incontinent I had to change her and keep her clean. For those of you who have never had to do this type of work I must tell you that it is back-breaking and time-consuming. Since Diane had no ability to move or hold herself up, she could not assist me. Needless to say the very nature of the duty tells you just how much of a mess it is (that was diplomatic verbiage don't you think?). One minute I was chain sawing a tree and the next putting a "Depends" on my wife. Now that is versatility don't you think?

Now I must stop here and address this care giving duty. When it first came to my attention that I had to do this

for my wife I freaked. Okay, I did this for Amanda as a baby and that was bad enough. At first it was a shock, but after a half dozen times or so you just do it and block it out of your mind. Diane and I had our most private talks at these times. We laughed and cried during these times. I know this may sound strange but we grew closer and closer each day. I fell more in love with her each day. She depended on me for her physical needs and I leaned on her for emotional support. She was always there to encourage me through this crisis. She always found ways to help make my job easier on me. She'd find people to take over some of the nastier duties so I could work or cut more trees.

Now most of you reading this have never had to totally take care of someone's bodily needs and I hope you never have to. It truly sucks having to do it. But if you go in to it with the right attitude ALL THE TIME the two of you will survive the situation. Keep in mind that no matter how bad it is for you it must be a thousand times worse for the person who needs these issues met. I can't imagine having someone wiping my butt a couple times a day, week after week, and month after month.

Around the time of the hurricanes Diane informed me I had to put in her tampon as she was losing the ability to insert it. She was sitting on the toilet one day when she delivered this bit of news to me. I said "you want me to do what"? Even though I had started cleaning her up on all the other bodily issues, this one completely caught me off guard. I looked at her and said "I can't do that". And as Diane always did, she looked at me and said, "you will and you are right now," with that little grin on her face she'd get when she knew she had me. I shook my head and said "okay, what do I do".

Now guys, I ask you, have you ever seen one of these gizmos up close? I hadn't. I never wanted to. I didn't care how they worked and didn't want to know how they worked. This was in the "no need to know" department for me. Well Diane starts to explain how you insert it in her and plunge and pull the string and stuff. "What? Do what with a string? You've got to be kidding me." Diane's crying she's laughing so hard. Keep in mind she's sitting on the toilet laughing and really, and I mean really, really enjoying this moment.

I am sweating, but being the caregiver that I am, I'm going to give it my best shot. Now in all honesty I must tell you that the first try was a disaster. I don't remember exactly what I did wrong but we had to go to a second tampon. I am so glad I'm a man. I can't ever imagine having to deal with this every month. Now Diane says she was always on time and regular with her period but I have to say it felt like her period came every week. I swear it would finish and then she'd call me in to the room a couple days later and I'd see her with that little smile on her face and she say "guess what" and I'd say "NO WAY YOU JUST HAD IT". She'd smile and say "no it's time". Oh my, oh my, oh my. I am so glad I'm a man.

Now dealing with a woman's period is bad but that's not the worse. I must warn you that the next couple of paragraphs might get a little graphic and for this I apologize. But the main purpose of why I am writing this memoir is for those ALS caregivers who read this get some insight for what they may have to go through. It is not intended to scare you but to educate you so you know you aren't alone out there and that others have had to go through what you will or are going through. And we made it through it. You will as well.

Okay, so here we go. Imagine Diane in her wheelchair when a case of diarrhea sets in. Now adult diapers do a pretty good job, but in these cases they need some improvement. And even when they contain the material the clean up is monumental, especially with a woman. Contents go places they should not go in a woman. On one occasion Diane had major material (does that description name work here? I hope so) up inside her vagina. This obviously is not good. I have to clean her. But how? I try the wipes but that only gets the stuff near the opening. I'm trying everything. Diane's laughing and I'm sweating up a storm. I was her entertainment during times like

this. I am baffled. How am I going to get this stuff out of her? It was way up inside her. Then I had a brain storm!! Ta dah! The turkey baster from the kitchen. She said “WHAT? NO WAY! I said “okay smarty do you have a better idea?” She didn’t so off to the kitchen I go.

I get a large pan of warm water to be inserted via the turkey baster and a second pan for the waste. Now these things look like super giant syringes or plungers depending upon your point of view. Needless to say I was cracking as many jokes at her expense as I could. This was my payback to her now.

For the next half an hour we worked and worked and eventually got her spic and span. I think we both lost five pounds in sweating and laughing. But you know something? We fell in love with each other a little more that day.

A lot happened around the time of the hurricanes and one of Diane’s major decisions took place about then. She decided to stop injecting herself in the stomach twice a day with the experimental drug IGF-1. Actually, at that point, we thought that either she has the placebo, or that the drug just wasn’t working. Diane knew her body and realized the disease was steadily progressing. Others, including myself, only saw the later part of a limbs paralysis. She could feel it weakening a little more each day. But she kept it to herself.

Her decision to stop administering the drug, I think, was also because she wanted to relieve me of that particular burden. I’m sure she knew I was handling more that I could possibly handle as it was. We really didn’t talk too much about her stopping the program as we both felt the same way. Why continue the injections and the hardship and pain that came with them only to see it not do a damn thing? For us at the time it was the right decision. Since Diane’s death IGF-1 hardly gets mentioned anymore that I can see in the research.

Okay back to the aftermath of Hurricane Charlie. It was a race against time with FEMA. They didn’t tell anyone in the neighborhood how long they’d keep picking up the trees curbside, so all I could do was keep cutting and getting them to the road. By the way, please understand that Diane and I lost several hundred Sand Pines on our five and a half acres. So here we are cutting trees and no power to the house for nine days. Finally, one day we see a power crew and they tell us within the next twenty-four hours we should have power. We did and for the first time in nine days we felt like we made it. Then we listened to the news and the weather report. Hurricane Francis was heading our way.

Diane says she can’t take it and says she has to leave. I agreed with her. So Diane, Amanda and Amanda’s boyfriend, Alex, get on the road to go to Biloxi, Mississippi to a hotel. There she meets up with my dad and step-mother. I decided to remain home to keep watch on the house, the dogs and keep cutting the trees. Well Francis was slow as molasses. We lost electricity in the beginning of the storm and didn’t get it back for seven days. In the meantime, my family is crowded together in a hotel room trying to cope with each other. For the most part they did okay. Diane has family in the Mississippi area and was able to spend some time with them. It was a good thing, as that was the last time most of them saw her alive.

I told them not to come home until the power was back on. This actually gave me a break from having to be the caregiver to Diane. Unfortunately, this job fell to Amanda who was just 15 years old. Diane and I had said all along that we didn’t want Amanda to have to do any of the “nasty” care stuff if we could help it. Well, she had to come to the plate on this trip, and she did so without complaining. Both Diane and I were very proud of her. I guess she has her Mom’s strength in her.

I’d like to say that during this time I was handling things well, but to be honest I was losing it. I had a terminally ill wife who was losing her battle to ALS every day and whose needs I was trying to meet, my business was suffering

quite a bit and I wasn't sure it would survive, the house had suffered over \$40,000 worth of damages, medical bills were coming in faster than the winds of the hurricanes, and here I was, cutting up trees in 95 degree temperatures. I needed some help. I needed someone to talk to.

Fortunately, I was able to talk to my ex-wife Terrie. Other than Diane she knew me better than anyone on this earth. She is a sweetheart with a heart the size of the state of North Carolina, which is where she lives. She was there for me every day listening to the latest reports of natural disasters from Florida, listening to me describe the decline of Diane's health and the sapping of my emotional strength. She kept me together from long distance which was no easy task.

Eventually the electricity was restored and my family came home from Mississippi. They were home just a few days when Hurricane Jean came a knocking. We all stayed home as Jean seemed to not be that strong, and there was nothing more that could be hurt around the house. All the trees were down and damage to house was caused by stronger storms so we figured we'd be okay. And we were except we lost power yet again. Then we had two small fires inside the house and the generator burned up. I lost it after that. I couldn't deal with it anymore. I told Diane I was taking her and Amanda to a hotel and I would stay and watch the house in case of another fire or theft or whatever else could happen.

I must admit that this was not my finest hour. I had been fighting all of this hurricane action for six or seven weeks now and things were only getting worse. I had nothing more to give.

I'll never forget what happened next. We were outside the garage and Diane wheeled over to me and very quietly told me to lock the house up and get in the handicap van. Let's go find a hotel, she said, even if we had to drive hours to find one. I did what she said. For the first time in weeks, we got lucky; we found a handicapped accessible hotel room not fifteen miles away. We only needed to stay one night. We got up late the next morning, had a great lunch and went home to see if we had electricity. We did. We cried and laughed. We made it.

During those six or seven weeks I learned a lot about myself and a lot about Diane. It was rough. I'm not a good enough writer to tell you, the reader, just how hard those days were. With all the damage and hard work the hardest part was the worry of losing my beloved wife. I had to see her suffer under very challenging conditions and there was little I could do. I felt totally useless, and as I became mentally fatigued I felt even more inadequate. But having said that I know that in my heart Diane knew I was doing the best I could with what I had in me. I fell in love a little more with her for that unconditional love and trust she had for me.

One day in October 2004 I was up in my office recording a talent doing a voice over for a commercial when the phone rang and it was Diane downstairs. It seems she had been adjusting herself in her power wheel chair, by reclining the back all the way back, she could use gravity to reposition herself in the chair without asking anyone else for help. Today, however, her arms fell out to her sides and she couldn't lift them back in and up. She said she tried for some time but they just dangled out by her sides, meanwhile her head was lower than her feet. Fortunately, the wireless phone was within reach so she called me to help her.

I realized on that day that the time had come to get help. Diane needed a full time companion to take care of her. How could I run my business and take care of Diane's every need 24 hours a day? Once she was righted back in position she made some typical "funny" comment and we all laughed. But deep inside we were both scared. This can't be happening.

Diane's mom, Monica, and her grandmother, "Mama," visited shortly after that day and took Diane to the mall.

They were in one of the department stores when Diane asked her mom to help her put on a sweater as she was cold. Monica has a bad back and was struggling to help Diane when a sales girl offered her assistance. Her name was Tricia and she took control, moved Diane the way she needed to be moved and in no time the sweater was on Diane. Monica and Diane remarked on her ability to manipulate a disabled person. Tricia said she had some prior experience from working at a doctor's office where she had to help many handicapped patients.

Well Diane did a preliminary interview right there on the spot and then gave Tricia her card. She told her to call if she was looking to maybe change jobs and take care of her. The next day Tricia called. Now I have never interviewed a person for a care giving job and wasn't really sure what to ask. Diane said she felt really "good" about this girl and we should hire her. I agreed, all the time wondering where the money was going to come from to pay her salary. We were tapped out. The insurance money from the hurricanes was all I had to pay for Tricia. I figured that some of the damage to the house could wait.

Tricia started the next day and I showed her how to do what needed to be done to take care of Diane. Since Diane still had movement in her arms and hands, Tricia's job was mainly to assist Diane.

Tricia and Diane got along great. They laughed and confided in each other. Tricia was in her early 20's while Diane was in her early 40's but they both seemed to be the same age. Diane really liked Tricia even though Tricia was truly "dizzy". Sometimes she was smart as a whip and other times very naïve. It made for some hilarious times as we all teased her constantly. Not to be out done she'd give it right back.

All was fine with Tricia till early December when she took off to Kansas City with some guy to go to an NFL Football game. She was due back to work Monday morning and she didn't show up. She called Tuesday with some excuse as to why she wasn't there but we didn't buy it. She left us no choice but to let her go which we did when she came back.

Now firing someone whom you truly like is very hard to do. Diane said she would do the deed and didn't want me around as she knew I was hurt and very upset over this episode. Diane's close friends Anne Marie Lentz, Kelly Schwartz and Michelle Denny were there in the family room with her when Tricia came to work on Wednesday. Diane was calm and let Tricia know just how disappointed she was in her and how she felt so used and let down. They both cried and Tricia left.

Well now we're back to square one with needing a full time caregiver for Diane. The holidays were coming, so finding someone was going to be quite tough. I called any "leads" I could find and interviewed several people. I was a little more wise on what to look for this time, and but we just couldn't find the right person. One of the "leads" we got at this time was for a nurse who was between jobs and lived very close to us named "Tia." I called her and got her Mom who said she was away in Iowa for several weeks. So, I moved on and forgot about this Tia girl.

Around this same time Hospice brought out a breathing assist machine called a "BiPap". This is an amazing machine. It somehow senses a person starting to breathe then sends air through the nose piece into the nose and then to the lungs. All of this happens in micro seconds. Diane was starting to get lethargic and have difficulty "catching her breath" in the afternoons, so Hospice thought this might help her be more comfortable. It did. Diane used it most days in the late afternoons for an hour or so then wouldn't need it till the next afternoon.

The interface between the machine and Diane was this "space- looking face mask" that truly could scare little

kids. First, she tried the total face mask that covered her nose and mouth at the same time. She had difficulty with this; keeping the mask airtight was a challenge as Diane's face was so tiny even the smallest mask was still too big. In order to make it airtight, parts of the mask cut in to her face causing bruising and cuts. This was not satisfactory. Eventually, she switched to a "nose pillow" interface. These were little nozzles that fit in her nostrils and connected to the air hose. Though these "pillows" worked better, they still created challenges for Diane throughout her progression.

Also around this time Diane's dad purchased a mobility van for us. Previously I had been loading Diane up in to my Ford Cargo Van and strapping in the wheelchair. It worked but was not very functional or comfortable. This mobility van made Diane's and my life much better. She could go when and where she wanted as long as she had a driver. This she did. Diane was not going to let something like ALS or being paralyzed stop her. No way. She always found someone to take her shopping or to lunch or out for a cocktail. One trip she dragged Anne Marie and Anne Marie's sister-in-law, Debbie, to the beach. On the way home they stopped at the "Cabbage Patch" bar, an infamous motorcycle hangout near Daytona Beach. Diane said she always wanted to see what it was like inside. So they all rolled out of the van and went in. Her power wheel chair could rise up about 3 feet, so she raised it up as high as it would go, right up to the top of the bar. I'm told she laughed, drank and had a blast.

Many of Diane's friends took her everywhere she wanted. This gave her some "normalcy" in her life. She could still watch Amanda dance and perform. She could still shop with her mom and dad. Except for some paralysis and breathing issues, Diane did what Diane always did, right up to the end.

On Christmas Eve 2004, Diane, Amanda and I went to the TD Waterhouse Center for the Northland Church Christmas Eve Service. Diane had asked me to make sure she had the BiPap machine and to figure out a way to "rig" it up to run on batteries. I used my Video Batteries and an AC to DC converter in case we didn't have access to electricity.

About five minutes before the service started she asked me to put the BiPap on her. From that moment on she was never without that breathing apparatus. Only when shampooing her hair or brushing her teeth did we ever take it off. Her breathing was becoming her next challenge. Till the day I die I will always remember and associate Christmas Eve with that moment, it was one of the most affecting of this ordeal.

Heartbreakingly, her reliance on the breathing apparatus meant we could not see Diane's face. She had the cutest face and I loved looking at it and kissing it. The BiPap also distorted her voice, and as time went on she had other issues and that machine contributed to her stress. But without the BiPap machine she'd have been totally wiped out and her oxygen level would have been be critically low.

January 2005 came and we still needed a daytime caregiver for Diane. One day she said she really missed Tricia and could we give her a second chance. I said she had to be kidding me. I wanted nothing to do with Tricia again. She hurt all of us. We opened up our home and hearts to her and she'd done a lot of damage. But Diane, being Diane, said we should talk to her and if Tricia promised she wouldn't do that type of thing again we'd hire her back. I thought it was a mistake and told Diane constantly that it was. Moreover, Anne Marie and Diane did an online search and discovered Tricia had had a felony arrest for drugs. Oh man, "there's no way we can have her back" I said. Diane said "let's see if she comes clean, and see what she says." I called Tricia and she said she wanted to come back and take care of Diane; she said she really missed us. So one evening we all sat down and talked. She came clean about the arrest and promised to never let us down again.

Tricia and Diane were back to being themselves and seemed to be taking care of each others needs. Tricia took care of Diane's physical needs while Diane gave out advice on relationships and life.

On January 14, 2005 (Diane's Birthday), Kelly Schwartz and Michelle Denny, two of our closest friends, threw a fundraising dinner party at Kelly's house. At first I was opposed to the idea of a fundraiser, as it really was publicly showing how financially drained we were at that time. I guess it is my upbringing. I didn't want anyone to know that I couldn't provide enough money to give the necessary care to Diane. Diane and I went round and around about this. I was extremely uncomfortable, and she kept saying that she understood but we didn't have a choice. We needed help. Most of our money was gone and nearly all the lines of credit were maxed out.

Because Diane's care was more important than my pride, I agreed to the fundraiser. It was a wonderful event. All of our friends were there and lots of folks we didn't even know. Michelle Meredith, a local TV reporter, was there to "host" the event. Diane and I had played her wedding some years before and she was fantastic in keeping the event going. She brought along the medical reporter from her TV station, Dr. Todd Husty. He explained what ALS is while Michelle Meredith kept the evening light and fun-filled. To this day I have no idea how much money each person donated. The funds were deposited into Diane's bank account and it was enough to get us through the next several months and postponed a lot of worry about money for a while. And when those funds ran out, an anonymous donation came in the mail one day. I couldn't believe it.

The amazing thoughtfulness and hard work from our friends Michelle and Kelly allowed us to have a small financial cushion, but most of all it showed us just how wonderful people can be. These two wonderful ladies gave so much of their time and resources to help their friends who were in trouble. I will be forever indebted to them for their incredible act of giving.

Perhaps because of the business I was in most of my career, I had become extremely cynical. Agents, managers and club owners were always lying to you to make a dollar. After years and decades of deceit you get quite distrustful. I was always wondering what these people wanted from me? No one ever did anything for anyone else, right? The music business had turned me in to a person who only believed people were out for themselves. I remember Diane's parents telling me over the years how big name entertainers and parishioners would give money and large expensive items to their church. My thought was "I wonder what those people wanted or were after".

Around January of 2005 we became aware that Amanda's school had raised funds for us as well. We knew nothing of it. I was probably kept in the dark about this because everyone knew how I felt about charity. I am a proud man and I hated the thought that I could not take care of my family. But one day I found out the well was dry and all my resources were tapped out. Diane asked me to call the school and see if she could address the student body at an assembly. The school, of course, said yes. In the meantime, Diane grabbed Tricia and off they went to get a plaque that could be given to the school showing our gratitude for the incredible, compassionate and thoughtful gift they gave to our family.

Diane, Amanda and I went out on the Trinity Prep School stage and you could have heard a pin drop in that room. You see a good many of the students knew Diane, or at least knew that Amanda's mom was in trouble. But when Diane was wheeled out wearing the BiPap mask, hose and machine the "kids" went totally still. Their mouths were open in a state of shock. Diane had prepared a speech; Amanda held the paper and I held the microphone while Diane read her words.

"Several weeks ago Mr. Hearn presented our family with a loving gift collected by the students and faculty here at Trinity. Your generosity has overwhelmed us.

Having a disease like this is a devastating experience. Sometimes life presents us with challenges. These challenges can be seen as an opportunity to teach us to be more patient, have more compassion, and to love more

deeply. Now, more than ever, I choose to look at the positives that surround me in life, and not to dwell on the negatives.

One positive, in particular, is the number of people who have come together to show their love and support to our family. You have made such a large difference in my life and in my family's life. I cannot begin to tell you how thankful I feel.

This support has given us the ability to obtain a full time caregiver as well as ease the cost of medical expenses.

Trinity is often referred to as your second family and I know that in our lives we truly feel that we are a part of this family.

Thank you for your love and support, not only towards us, but, in particular, towards our daughter, Amanda, which you show on a daily basis".

After she read her speech many of the kids rushed the stage to hug and kiss "Amanda's Mom". Diane teared up, smiled and told each one how much she loved them. Much thanks goes to the drama teacher and longtime family friend Janine Papin for spearheading this initiative.

A few days later Janine tracked us down and said she had been given a note from a young girl and asked her to deliver it to the LaMotte family. It read:

Dear LaMotte Family,

My name is Anne McCarthy and I am in the 6th grade at Trinity Prep. When you came in to say thank you for the money we raised, it touched me. I couldn't imagine having ALS, especially since I'm a soccer player. I have enclosed \$500.00 to help with your needs. I was going to use it for my own needs but I saw that your need was much greater than mine. I wish you the best of luck!

Sincerely,

Anne McCarthy

Needless to say we were all speechless. This sweet compassionate little girl didn't even know us, but she realized at such an early age what is so very important in life—that we must take care of one another. If everyone in this world could be like Anne McCarthy we would have a much nicer world to live in. Once again, thank you Anne McCarthy for being a shining light for the LaMotte family at a time when there was so much darkness. Amanda and I will never forget her for as long as we live.

It was also around this time Diane decided she wanted a feeding tube put in her stomach in case she got to the point that she couldn't eat solid food anymore. I was totally shocked. Yes I had heard of other ALS patients having this done, but that was because they couldn't eat regular food. At this time Diane could. She made her wants known to Hospice. Dr. Jay our Hospice Doctor immediately made an appointment with us to discuss this.

Now Dr. Jay is a smart and wonderful man. He is incredibly compassionate, especially for a doctor. Diane and I always felt secure in his suggestions and treatments. But concerning this feeding tube issue, he wasn't sure Diane should have one. His biggest concern was the Terrie Schiavo syndrome, he asked whether, if the time came, anyone would be prepared to order the feedings stopped, and in so doing, end Diane's life. Diane said she wanted the

feeding tube because it might give her more time to be alive and with her family and friends. Diane said it was strictly a precaution.

Dr. Jay and Diane went around and around. Diane held her ground and eventually, like everyone who knew Diane, he “came around” to her way of thinking. We always joke that Diane is always “right”. And in this case she was 110% correct. That feeding tube did give her extra time on this earth and an easy way to receive medications later on.

Dr. Jay’s main concern was whether I had the “guts” to give an order to stop feeding. I said I could if that was Diane’s wish. I could do it because I loved her. I guess he understood so he ordered the procedure to be done.

Diane’s biggest concern was something that we had read about early on, which to be honest, I had forgotten, some patients who need a feeding tube wait until it’s too late to get one. A patient who is completely dependent on oxygen or a BiPap cannot be given anesthesia. Installing a feeding tube is a relatively quick procedure, but for some patients it might still be too long to be off the “air.” Diane remembered this, and sensing that her breathing was becoming more and more labored each day, wanted the feeding tube installed before time ran out.

The procedure went smoothly but the recovery didn’t go as planned. Originally, the doctors said it would be an outpatient procedure, and then it became a one day stay, but ended up taking two and a half days. Diane was miserable. The tube hurt and made care giving very difficult. I’ll never forget the first time I saw this tube sticking out of her. It made me cringe and feel sick. What was happening to my beautiful Diane? She had tubes sticking out of her, a mask over her face and a steady “whine” of machinery all around her every minute of the day.

When we came home Tricia had erected a banner saying “Welcome Home Diane.” I was never so glad to be home and I know Diane felt the same.

Thereafter, everything was going along pretty steady when another problem strikes. Remember what Tricia did a few months earlier? What happens a week or so after we bring Diane home? Off Tricia goes again with another guy and leaves us hanging. It is in Diane’s spirit to give people a second chance, but this was unacceptable. We fired Tricia and have never heard from her again.

So, I was back to looking for caregivers again. Someone tells me to call a local community college that has a nursing program, maybe I can find a nursing student who needs a job. I did and that’s how we were all introduced to Jana’ Kanerova from the Czech Republic. The same day I tried that “Tia” girl again and actually spoke with her. I told both of them the situation and asked if they would be interested in interviewing to take care of my wife. Jana jumped on the opportunity but Tia was very non committal. She was so non committal that I said to her “when you decide if you want to do this call me.” I blew her off and continued to look for others. The next day Tia called and after prodding it out of her she said she’d like to interview for the job. I scheduled Jana’ and Tia the next day to come in and talk to Diane and I.

Diane and I interviewed Jana’ first and found her very delightful. She came loaded with government work permits, International Student Visa documents, references and a Justice Department report. When she gave us the report stating she had no felonies or other crimes against her Diane and I looked at each and smiled. What a difference between Tricia and Jana’. Tia’s interview also went well; she was quite quiet but seemed confident and overqualified for the position. I called them the next day and got them on the schedule.

In the beginning, and for most of the seven months they were with us, the two nurses split the hours each day in

half. I let them work out their schedules as long as we were covered every minute of the day. Each nurse had a different style in caring for Diane but I knew she was always in competent and compassionate hands.

The duties for the nurses Jana' and Tia were quite easy in the beginning. Basically be Diane's companion, keep her clean and change the TV channels as she commanded. Diane was still in charge of the household and she made sure everyone knew it. She did this not in a mean way but in an easy but firm way. Judge Judy and Wheel of Fortune seemed to be her favorite TV shows. She needed the sound turned up high because of the BiPap machine noise as well as the air being sent in to her lungs.

The doors of the house were in a constant state of opening and closing. There was a constant supply of medical people and friends visiting. This only increased as Diane's disease progressed. By June 2005, she began to be struggling for air quite a bit. The Hospice people ordered morphine to be administered. This doesn't do anything to solve the lack of air issue, but does calm the patient down so she can cope with the feeling of "air hunger".

Also around June of 2005 Diane had reached the point where eating solid foods became impossible. This was a very quick transition from eating without difficulty to choking even on soft foods like applesauce. The hospice medical staff prescribed cans of "Ensure" to be administered via the feeding tube. Remember, up until this point, she had had this tube but never used it. Had we waited till June she couldn't have had it inserted because her breathing had become too erratic to be able to survive the surgery. Once again, Diane was right and had made the correct decision to have the tube inserted months earlier.

In treating yourself or caring for someone else you must be proactive and question every decision or medication the medical staff prescribes. In Diane's case the caloric intake of Ensure was less than I felt was adequate so I pushed for a higher caloric intake. Reluctantly, Hospice prescribed Ensure Plus which added extra calories per can. I thought that I was being proactive and this was the best thing for Diane. In reality, Diane didn't really care one way or the other but let me go about my crusade.

I remember that there were many times that she just couldn't take the entire can. Her stomach was full. Now keep in mind that the sensation she was feeling must have been very strange and just plain "weird" when it came to being fed via a tube in the belly. But when she was full she let you know it and the Ensure just didn't want to go down.

I just recently found out (approximately 16 months after her death) from Karen Delisle the Hospice nurse that several weeks before Diane passed away she had asked her if she could cut down on the amount of Ensure because she thought she was putting on weight and that she didn't want to be any heavier. And she asked Karen not to tell me because I had been such an advocate for more caloric intake and she didn't want to hurt my feelings. Just a few weeks before her death, there she was, being a typical female worrying about her weight. Incredible!

In reality I think she started losing weight. She definitely was losing muscle mass. Her legs were getting skinny. The rest of her seemed the same.

That feeding tube gave Amanda and me about three more months with Diane. Without it she couldn't have eaten naturally and medication would have had to be administered by needle instead of through the tube. Her last weeks would have been miserable and painful. Diane's careful online research and her natural instinct to eliminate fear about her disease allowed her to make a decision that kept her alive with a better quality of life for a few more months. The feeding tube also played a huge role during her last fourteen hours alive. More on this later on.

At this time I would like to address an issue from my experience and questions asked by other ALS caregivers I've spoken with. The question we all have asked is "When can I expect my loved one to die? What will it be like? What can I expect? That first weekend I found a great "tell it like it is" ALS web site. Unfortunately, I didn't bookmark it and I was never ever able to find it again. Luckily I talked with Julie Steele at the University Of Miami Neurology Center and she was extremely forthcoming with real hard facts. The short answer to those questions is no one really knows when or how the ALS patient will die. Each case is different. Some suffer with a traumatic death while others go quietly.

In the fall of 2004, Diane was progressing fast, and I was in desperate need to know what was going to happen. I dwelled on this almost to the point of an obsession. Of course, Diane didn't know this but to every medical person who came to the house or I spoke with on the phone I asked these questions. How much time did she have? How will she go? I needed to know so I was ready and prepared to make it the best for Diane, Amanda and myself.

Understand that I had taken care of her for 22 wonderful years. I needed information so I could take care of her the best that anyone could to the very end. I was frustrated because those that knew the answers either wouldn't or couldn't answer. So I called Julie Steele again. Having met Diane when she could still walk (albeit with a cane) and then to be where she was in her disease by late Fall 2004, Julie gave me her best guess. She said she thought that maybe Diane would make it to July or August 2005. She gave me typical scenarios of how ALS sufferers pass on. As usual Julie was very upfront and honest. And eerily accurate as it turned out.

In June of 2005, Diane's condition was very bad but she was hanging in there and fighting the best she could to not let the disease have the upper hand. By this point she was a total quadriplegic, her breathing without the BiPap was very stressful and her breathing with the BiPap was more labored than it had been in previous months. Her speech was starting to sound slurred and the secretions (saliva) were building up in her mouth and throat. Diane and those around her knew she was getting closer to the end.

I specifically remember one late afternoon visit with the hospice nurse Karen. Diane was in the family room and Karen and I were in the master bedroom and I asked her my questions. How much time did she think Diane had? She couldn't give me a month no matter how much she wanted to. She just didn't know. Also, because every ALS patient progresses differently how could she know? Karen and I talked again about a "tracheotomy" with artificial ventilation. But Diane had made it very clear to everyone she didn't want to be kept alive by artificial means. I said this to Karen and I'll never forget what she said, "Keith, Diane's being kept alive by artificial means now. The BiPap, though only considered a breathing assist machine, is keeping her alive".

At that moment I realized for the first time that this was real. It was going to happen and it was going to happen soon. The medications were getting stronger and there were more of them; Diane was having more issues like increased air hunger, pressure sores (though hospice, Tia and Jana took incredible care of these and never let them get too bad) muscle cramping, and throat issues. Every night the medications went from none to four or five with increased dosages.

I'd crush up some pills, dilute some liquid meds and mix with this medication and that medication. Every week the nighttime and daytime "cocktails" got more complex and with higher dosages. Then I had to clean the tube with water, put medication on her where the tube went in to her so a sore didn't develop.

We had a routine which was the same every night. At 11pm I'd put her to bed (if she wasn't already there) and make sure she was clean and comfortable with the 11 o'clock news on. I'd go in the kitchen and start creating the "cocktail". This usually took 10 to 15 minutes or so. Then I'd come in and sit with her for a bit until the news

was over.

Then I'd start administering the "cocktail" into the feeding tube. While I would do this the "Tonight Show with Jay Leno" would come on, and I'd say "There's Lee." Lee was the trumpet player in the band and longtime friend of Diane and her family. In fact, Lee played for her dad for years and was a member of the CC Riders. She'd say "hi Lee" and by the time the first commercial break happened she was out like a light.

It's funny how certain times and experiences play in your mind and your heart. I came to truly love this time with her. I don't understand why but just writing about this right now brings tears to my eyes. I guess these few minutes each night were all ours and nobody else's. All day and part of the night there was usually a medical person or a friend there at the house visiting Diane. Amanda was usually asleep by that time. This was "our time".

After she was asleep I'd clean up what had to be cleaned up, straighten the bedroom the best I could, then crawl in beside my wife. As I mentioned before, Diane refused to lie in a hospital bed. It would have made her more comfortable and easier on the caregiver and nurses but she was adamant. No hospital bed for her until the end. So instead we had an automatic elevated mattress pad designed for her back and head. It is hard to explain but only her back and head were elevated. She slept almost upright because she was to the point that if she was fully reclined, the weight of her internal organs would push against her lungs and smother her and she didn't have the lung capacity to push back that internal weight.

So I'd get in bed and just put my head on her shoulder and wrap my arms around her and fall asleep. Or try to anyway. Because the thought of sleeping at night by this point in the progression scared me.

4am

Almost every night around 4am a crisis seemed to occur. As her disease progressed the events became more dramatic. Sometimes the event was extreme nerve pain that Diane described as a hot knife stabbing in to her. Sometimes this feeling was in her legs, arms, shoulders, knees and lungs. Another crisis, especially toward the end, was "air hunger". She'd wake up gasping for air. Keep in mind she wore the BiPap all through the night. She wore the BiPap twenty-four hours a day. But even with this amazing machine called the BiPap and the Oxygen machine running she wasn't getting enough air. Other times it was her choking on her own saliva. She was losing the ability to swallow. In a given minute count how many times you swallow. Diane was having trouble doing this even once.

Sometimes all these issues were happening at the same time. Hospice had the medications to ease her stress and had given me the instructions of what to do when this all happened. I must say though that when your wife is hysterical and trying to ask for "something" but you can't understand her because she is losing the ability to talk, panic sets in real fast. Usually, the morphine was the answer. It calmed her down enough so I could handle the other issues. As time went on she required stronger doses of morphine to allow her to "cope" with the air hunger issue.

Hospice was always just a phone call away. We only had to call in the middle of the night a few times when nothing was helping Diane's stress at all. They'd usually tell me to go open the "comfort pack" and administer some drug that was contained inside. The "comfort pack" was a small box that had really unique and powerful drugs. It had to stay refrigerated and was only to be opened and used in an emergency and under Hospice instructions.

One night about 8pm, Diane asked me if her eyes were going back and forth. I looked at her and her eyes were going back and forth faster than you could ever try to do. I couldn't believe what I was seeing. It was a Hollywood special effect only this was very real. We hadn't been warned about this kind of event. First thing I did was call Tia. She was at her church but she said she'd "get her car and be right there". She suggested I raise Diane's legs up high to get blood to her head. I did this. Outwardly, I tried to stay calm but inside I was freaking out. Tia was there in 15 minutes and took over in her usual calm way.

Diane's eyes had slowed down and she seemed to be feeling better. Tia took her blood pressure and it was low. She called Hospice and together they tried to figure out what had happened. Every so often Tia took Diane's blood pressure and it continued to rise. Both Hospice and Tia researched the medical books on hand wondering if one of the medications could have caused this event. They never found a reason why Diane's blood pressure dropped so suddenly and luckily it never happened again.

I wonder how I was able to function the last 4 months of Diane's life. The emotional strain and lack of sleep were really taking its toll on me. By the time, Diane passed away I was in a state of mind that I couldn't trust my judgment any longer and depended on others for their opinions.

In the middle of July 2005 one of the remaining two occasions occurred that I believe Diane was determined to experience before "letting go." This was her dad's band reunion which occurred every two years in south Florida. She really wanted me to go but I had a business commitment and couldn't take her. So her great friend AnneMarie and Tia packed her up in the mobility van and off they went. I was on edge the entire time they were gone. I was afraid that something might happen and I wouldn't be there for her.

The hotel they stayed at was incredible. AnneMarie had called ahead and told them they needed a handicap room with a hospital bed and other specific items. They went above and beyond accommodating Diane and her needs. I was in constant touch via cell phone checking in to make sure she was doing okay. Diane really enjoyed herself from what I was told. The CC Riders and their wives and friends were incredible. Many of these musicians saw Diane grow up from a little girl and considered her one of their own. And some of the Riders remember Diane singing in the band years back. It was a great event and I am so glad Diane went and was able to say goodbye to these special people. This was also the last time she visited her dad's church. Everyone knew she probably would never make it back and they all loved her and prayed for her.

So, everything went fine on this trip and back to Orlando she came safe and sound and no problems. Well, almost. After she was home for a couple of hours AnneMarie and Tia finally confess there had been a situation. They proceeded to tell me that just before they left to come home they had lunch with Diane's parents at a restaurant. They ate and as they were saying goodbye to Diane it started to rain. At this point Tia and AnneMarie are trying like crazy to get her in to the van before she gets wet. While they are cruising across the parking lot rain hits the battery system and shorts out the BiPap machine. Diane can't breathe.

As AnneMarie tells the story she was okay till she looked in Tia's eyes and saw major panic which in turned scared the "you know what" out of AnneMarie. What had happened was it seems the rain shorted out the DC to AC adapter. Unfortunately, Tia didn't know this and thought that the batteries were dying. I had given them plenty of extra batteries. She quickly changed them out. No good. Still no power. They hook up to the cigarette light jack and still no power. Now they realize the problem is either the adapter or the BiPap machine. Keep in mind this is July and the BiPap had been running almost nonstop since Christmas Eve 2004. That's seven months of running and providing excellent service.

Now while all of this is happening Diane is struggling. Fortunately, every twenty to thirty seconds or so the machine would go on for a few seconds then shut down. But this was just enough to keep Diane breathing. The three of them found a Radio Shack after driving for 15 minutes and bought two new adapters, plugged one in and the power came back on. Diane could breathe.

This was a close call. As they are telling me this I'm freaking out, but Diane is smiling at me. Actually, it was the mischievous smile she'd get when she wanted to be ornery. The first thing I asked was why didn't they take her back inside the restaurant and find an electric plug and plug the BiPap in? They both looked at each other and said they didn't even think of that. I'm sure my Monday morning quarterbacking was not particularly welcome.

The rest of July and August is a blur to me. I was doing my best to appear strong and in control in front of Diane and everyone but internally I was losing it. One afternoon I told Tia I didn't feel well. She took my blood pressure and told me I was only 2 points away from being in the emergency room. It was that high. She told me I needed to get to a doctor right away. I said I would go in the morning. Since Diane had a friend looking after her, I took a walk around the neighborhood in order to calm down and hopefully lower my blood pressure.

I remember that walk very well. I cried and shook uncontrollably. I was losing it physically and mentally big time. "I've never felt like this before. What is happening to me?" I asked myself. After about a half hour one of my neighbors stopped me as she was driving by and asked about Diane. She could tell I was a wreck and just talking to her helped me a lot at that moment. After we finished talking I walked back to the house and sucked up my "feeling sorry for myself" look and went to Diane and took back over her care.

The next morning I went to the doctor. As soon as she walked in to the room she asked me what was wrong and I lost it. I just broke down and cried like a baby. I didn't have any strength left in me. All the energy, all the strength and all the fortitude was gone. I told the doctor to give me whatever drug there was to get me back in control so I could take care of Diane. She started me on Zoloft but a very mild dosage. This Zoloft takes a few weeks of being in your system before it does any good. After one week I went back and told the doctor I needed something to act quick and fast because Diane needed me now more than ever. I didn't have weeks for this Zoloft to kick in. The doctor gave me Xanax and after a couple days it seemed to calm me down.

Tia and Jana continued to take care of me along with Diane. Diane never knew how emotionally drained I was. She only saw the "got everything in control" Keith. She did know my blood pressure was high and she was concerned about that. I assured her the doctor and I had it in control and to not worry about me. She had bigger things to worry about.

During all these months Amanda stayed very busy with shows. She seemed to go from one rehearsal to one show and back to another rehearsal. This is how she dealt with Diane's illness. I am so glad she stayed busy and really didn't know first hand all that was going on with Diane. She saw more than a young person should have to see at that age. Diane loved to listen to her tell about what role she had and what song she was having an issue with or some other actor did this and that. Amanda and I were still Diane's reason for living.

In early summer, Diane had asked for a private conversation with Karen Delisle the hospice nurse. Diane also had questions. Karen is an extraordinary person with an incredible wisdom. They were out in the bright sunshine on the lanai next to the pool. I watched them and wondered what was being said. But this I recognized was a special moment for Diane. I figured she was probing for answers about her death. I was right. Later, after her death, Karen told me that the main question Diane asked her was "How will I know when it's time?" Karen told her she'd

know when she put herself first and not Amanda and Keith. This had to be hard for Diane to accept. Her life was putting Amanda and me before herself. Her selflessness was her essence, her being and everything she stood and lived for.

Diane had also asked Karen about how she thought she would “go.” Would she choke or have a heart attack or just stop breathing? Of course, Karen had no way of knowing. The subject of “palliative sedation” was brought up and Karen explained what this was and how it worked. Another ALS patient we knew had been sedated and passed away with no violent complications and this appealed to Diane as an option. Throughout the summer Diane and I spoke about this “sedation” option. I was having major trouble with it because it sounded like “assisted suicide” to me. It sounded like Terrie Schiavo to me.

We questioned Karen a few times about “sedation” on her weekly (and sometimes two and three times a week) trips to our house. I just wasn’t getting a clear picture in my mind why this was a good option until Dr. Jay visited with us one afternoon. We had a very long discussion and many questions were asked and many tears were shed. This was probably the “heaviest” discussion anyone could ever have in this life. At the end, I finally understood what it was and how it applied to Diane and me.

But this was only an option. The next morning Diane started asking spiritual questions about “sedation.” How would God feel about this? Is this a sin? She was deeply troubled by the spiritual implications. Diane always held her faith close to her heart. We hardly ever discussed religion or God, and when we did, we differed greatly in our beliefs. But she respected my views and I hers. Now she started expressing and seeking spiritual guidance. So that particular morning I suggested that I call Mike Caroline, the hospice chaplain, and ask him to visit with Diane and answer her questions about God and “sedation.” Mike was there in an hour. Mike is a sweetheart of a man. He is one of the nicest and sincere men in this world. He always made Diane, Amanda and me feel special. He honestly and genuinely cared about all of our well being.

Before Mike arrived though, Tia was to be there to start her work day. Tia by this time was taking care of Diane 100% of the time as Jana had taken a job with Florida Hospital, and was only working for us on an “on call” basis. Tia and Diane spent many hours talking and laughing. They grew incredibly close. Tia’s faith is monumental. She was the perfect person to be placed with Diane during this period in her life and this period of her dying. I could write an entire book on what Tia meant to all of us in the family. She is incredible, with a gift of understanding, patience and humor.

Before Tia arrived, Diane said to me that she couldn’t even consider “sedation” if Tia was opposed to it. That is how much Diane thought of Tia and her faith. When Tia arrived I sat her down in the kitchen and explained what was going on and that Mike was on his way over to talk about the “sedation” option with Diane. Then I asked her what she thought about “sedation” both spiritually and medically. We talked for a while but she saw nothing unethical or ungodly about “sedation.” Mike arrived and the four of us had another long discussion.

What Diane was doing here was collecting her information. She was doing her research. I’m sure she would have been on line researching if she had hands, arms and fingers that worked. She also asked “The Rev,” who is the chaplain at Trinity Prep School to visit her. She asked all these questions and got an endorsement of “sedation” from her, as well. Diane then asked her to keep a watchful eye over Amanda for her. The Rev said she would and she has these sixteen months later.

Diane started drilling me about Amanda’s future and making me promise that I’d support her dreams. Of course she knew I would, but I don’t think she wanted to leave anything undone. One of Diane’s number one concerns was that I take Amanda to New York to see the Broadway show “Wicked.” This was something that Diane had

wanted to do and now knew she never would, and she wanted Amanda to see this show in the worst way. Five months after Diane's death, Amanda and I saw "Wicked." However, we almost didn't. Due to a mix up with days and times we had to give up our Wicked tickets for another show. The story is too involved to get into here but I ended up waiting 2 hours in the cancellation line hoping for a couple of last minute tickets on the only day we could see the show. Two minutes before curtain the ticket person calls me over and we have two tickets front and center. Incredible tickets to an awesome show. It makes you wonder if Diane wasn't pulling some strings, just as she would have if she was still alive.

In mid July Diane asked for me to "break out" the family videos so we could watch them together. So for the next two to three weeks we re-lived many precious family memories. Most of these videos were of Amanda and the holiday seasons with friends and family. Diane and I enjoyed them very much. Many of these video clips had never been watched before by any of us and it brought much happiness to the home between medical crises. Everyone who visited was asked to endure some video that Diane wanted them to watch with her.

Every once in a while I'd ask Diane if she wanted to watch any video footage of the show band. She always said "no, not now". She never did watch any band footage and I think the reason was she couldn't have handled seeing herself dance and sing as she once did. I believe it would have been too painful for her to view.

These last few weeks Diane and I discussed everything from Amanda, to business to funeral arrangements to "sedation." One evening I told her about an idea I had about starting a nonprofit foundation to help those families with ALS both with equipment and funds to help pay for caregivers. Diane and I knew how helpful our friends and families had been in keeping us from drowning in to bankruptcy because of the effects of this disease. Without them we would have lost the house, the business, our self respect, and Diane losing her life. To say it's devastating is an understatement. There is no way to describe how you feel when facing these challenges. I hope you never have to encounter something like this.

Anyway, she said "Do it, Keith. Give back for both of us." I said I would, and that was the beginnings of the "Diane LaMotte ALS Foundation". We talked occasionally about the Foundation but mostly she listened as I talked. She had pretty much lost her ability to speak by this time. But her eyes spoke volumes.

One morning in late August Diane asked me to call her parents and ask them to come up to Orlando because she wanted to discuss something with them. Then she had me organize a meeting with all the hospice medical staff to join her talk about "sedation" with her parents. I was opposed to this. Diane's parents have a very strong faith and I was afraid they wouldn't embrace the whole picture because of religious reasons. I was afraid that they would insist that "sedation" not be an option and to let nature take its course. Well nature taking its course would all likely mean a very violent ending for Diane. I didn't want them in the "loop" so to speak. I didn't want them to have a "say" in the matter. I feared a family squabble like what plagued the Terrie Schiavo case.

But as we always say, Diane was right. She explained it to me that this was her decision and hers alone, but she wanted her parents to understand what "sedation" was, how it was administered and why she wanted this as an option. As usual, I realized she was right and I made the call and asked them to come north. They did and all nine of us met in our bedroom. By this time, only 12 days before her death, Diane wasn't venturing out of the bedroom too much. Diane was in bed, of course, and I sat beside her and Tia was sitting in the wheelchair right on Diane's other side. We were her interpreters. It was hard for others to understand "Dianeese" as I called it. Tia was better than me at the end in understanding Diane. Most the time when Diane spoke she was cracking a joke. Sometimes it would take us five minutes to figure out what she was saying and only then realize that she'd been "messing" with us. She had a great sense of humor.

So the nine of us are sitting there, and after a short prayer by Mike Caroline, Doctor Jay explains to Monica and Wayne why we are there, and what Diane's wishes are about "sedation." Wayne and Monica questioned Diane intently, making sure that they understood her wishes. Because of their strong faith they believed that she would still be cured of ALS. In fact, they believed this until her last heartbeat. I know they were very disappointed. I know they temporarily questioned their faith, and, like all of us, asked "why?"

This meeting lasted a couple of hours and the Hospice people were terrific in their explanations and guidance. But at the very end I reminded everyone that this was only an option. One of the items to be discussed was Diane's wishes for after she had been put in a coma-like state. To listen to her discuss her desires and explain why she felt the way she did was gut wrenching, but at the same time I was in awe of her dignity and her spirit. Diane had been "in control" as best she could with this disease and she would stay in control till the end. No ifs, ands or buts.

Diane took me completely off the "hook" on having to make life deciding issues. She knew that scared me more than anything. She knew I was afraid to have to make a "call" and then later realize I made the wrong decision. By making her wishes known it allowed me to have some inner peace. This came in handy the last day of her life as it gave me strength I didn't know I had in me. That was my Diane. Even at end of her life she took care of Amanda and me. Always thinking of us instead of herself.

On Friday, August 26, 2005 Diane was able to experience the other reason I believe she "clung" to life and that was Amanda's opening in the Trinity Prep School production of the Broadway show "Urinetown." It took Tia and me a couple hours but we got her in the van and off we went. We got her situated on her aisle seat in the back because that's where the electric outlet was. Our friends from Orlando were there and our friends from Hospice were there as well. This was a very special night for sure. Just before the curtain went up Janine Papin, the drama teacher came out on stage and said that the cast of the show has dedicated opening night to Amanda's mom, "Diane LaMotte". The entire audience stood up and faced Diane. She started crying, and I started crying. We were both speechless. The applause went on and on. It was a moment and a gesture I'll never forget for as long as I live.

Of course, Amanda was brilliant (I may a little bit prejudiced) in the show and made Diane and me extremely proud. After the show all the cast members hugged and kissed Diane. They all wanted their pictures taken with her. Prior to getting sick, Diane was very active in the drama department, so most of the kids knew her.

On Saturday, Diane was too tired to make the performance. She wanted to but she was exhausted from the previous evening's outing. But on Sunday she was ready to go back. The evening of the day we had the "sedation" discussion with Diane's parents was another performance of Amanda's show. Diane's parents joined us in watching this performance. Just like the previous weekend Diane was too exhausted to make the Saturday performance. But on Sunday September 4, 2005 I got Diane dressed and we made the trip to Trinity for the final performance of "Urinetown".

Amanda was great. She gave it her all as she realized that this was the last time mom would probably ever see her perform. After hundreds of dance recitals, dance competitions, school productions, TV commercial shoots, dance classes and a national tour, this was the last performance. After the show, Amanda went to Diane and hugged and kissed her. A mom of one of the other cast members took a picture of that moment and later framed it for Amanda. It sits next to her bed every night.

So, just as she was determined she would, Diane made it to the second event she'd wanted to experience before the final curtain.

The two of us talked a lot about life and the future without her. As husband and wife we talked about very personal things and hopes and dreams for Amanda and me. It wasn't until after Diane's death did I realize she gave me the greatest gift she could have given me. And that was her wish of a life of total fulfillment for me. She knew I am a person who enjoys life with a companion. So she gave me her support in letting me live and hopefully one day find love again and be loved back. Her only request was "take care of Amanda." Of course, that was and is easy to do, since I love her more than life itself. I will always watch over her, for the both of us. Diane lives in Amanda. I see it more every day. Amanda has Diane's unique ability to reason and to express herself in no uncertain terms. I expect as she gets older more of Diane will emerge. I can't wait for that. A more deserving honor I can't imagine could exist.

On Friday September 9th, around 10pm Diane stopped breathing for a few seconds. I had just walked out of the room for a minute and when I returned she said "I stopped breathing." "What's that mean?" I asked. She didn't really answer. I felt totally lost. I didn't know what to do. Her breathing was okay now, the best I could tell. I remember going and telling Amanda. We both just looked at each other, speechless.

Saturday, I spent the entire day with Diane in the bedroom. She slept a lot and later I fed her, bathed her and we talked while she was awake. We both watched the Hurricane Katrina coverage on TV and were shocked at what we saw taking place in New Orleans and Mississippi. She has family in Biloxi and she was panicked for a few days until she heard they were all okay. Ironically, just six weeks after Diane died, her twenty-six year old cousin Monica from Biloxi passed away. "Only The Good Die Young," isn't that how the song goes?

Sometime that Saturday, Diane told me she wanted to go to church on Sunday. I asked whether she was sure, because I knew it would take a lot out of her. She said "yes" she was sure. All day Saturday I sat next to Diane and the two of us talked and watched TV. She slept off and on but overall the day was a good day for the two of us to just be together. I didn't realize just how close we were to the end. I look back on that weekend and can't believe I was that unaware that her passing away was just hours away.

It was a beautiful Sunday morning as I started getting Diane ready for church. The previous night had been typical with its 4am interruptions, but overall it was our "normal" type of night. I started getting her cleaned, bathed, fed and dressed at 8:30am. Diane had asked our friend Janine Papin to join us at Northland Community Church for worship service. At 10:30am, Amanda and I had finally finished getting Diane secured in the van. We had driven only a couple of miles when we all realized just how much trouble Diane was having breathing. Also, we had forgotten a neck pillow that supported her head and it was bouncing all around. Amanda actually had to come forward and hold her head as we drove on. Ten minutes after we had left the house she said she couldn't take it and to take her back home. She was wiped out. This was Diane's last car ride.

We got her home and it took me a good 45 minutes to get her back in bed. She was totally exhausted and fell asleep right away. I sat with her all day while she slept. In the afternoon Tia called and said she was bringing dinner. I can't tell you how wonderful that was to hear. Cooking dinner was the last thing I wanted to think about. I didn't want to leave Diane alone in the bedroom. Amanda was close to home all weekend and especially nearby that Sunday.

Around 6pm Tia and her parents and a close friend came and brought us a wonderful dinner. We all sat down at the kitchen table for supper, but every few minutes either Tia, Amanda or I went in to check on Diane. She continued to sleep. She had now slept about seven hours since our venture to church. I had never seen her sleep so long since she had been sick. Around 8pm Diane woke up and was bright and chipper and spent a few minutes entertaining

(as best she could) her guests. We watched some TV then went to bed as normal.

Monday the twelfth of September 2005 was a typical day. The Hospice people all came and took care of business. I tried to work but found myself most the day downstairs with Diane and the medical people. At 9pm that night I lay down beside Diane and asked "What are you ready for?" This is something we always did on Monday nights since it was Monday night football. She replied as best she could, with a smile on her face "Are you ready for some Football?" We both laughed and I put my head on her shoulder and started watching the game. About 45 minutes later she said "Keith, I stopped breathing." I didn't say anything. I just looked at her and she looked back at me with fear in her face. After a minute or so she said it again only this time with a little more panic in her voice.

Now I'm getting a little freaked out here, but I'm trying to stay in control and not broadcast my concern. I'm sure Diane saw right through this, as she could always read me like a book. I eventually laid my head back down on her shoulder and we continued to watch the game. About five minutes later she again said she stopped breathing. Only this time when she said it she was quite upset. She looked at me and said "Go get Amanda. I need to say goodbye and call Hospice, I want to be sedated NOW." I said honey, are you sure? She said very emphatically "Yes. Go get Amanda".

I am totally panicked at this point. I'm emotionally drained from months of worry and crisis and now when I need to be the strongest I can't reason or think straight. I'm scared. I don't know what to do but I figured Diane knew what was best so I got Amanda. I told her Mom had stopped breathing three times in the last ten minutes and that she wants to say goodbye and to go to her quickly. I then call Tia. Somehow I get it out and tell her what is going on and she says to call the hospice nurse Karen. Now, I think it's against the rules for the hospice nurses to give out their private cell phone numbers, but Karen had done so a few days earlier when I had asked. Diane had made her promise that she would be present in the last hours. I begged her to be there as well. She had instilled confidence in Diane and me, and we knew we could both go through this as long as Karen and Tia were there.

I called Karen and she was calm even as I was spouting out nonsensical speech to her. I remember that phone call as if happened just a few minutes ago. I pleaded with her to "knock " Diane out, but she said it takes time to start sedation and a "crisis" team had to be assembled. Karen told me to just give her her regular nighttime medications that would put her asleep. Maybe she would pass in the night. "Okay," I said as if this was an everyday occurrence.

I went back in to the room and Diane was finishing talking to Amanda. Only once did I ever ask Amanda what Mom said to her that night. Amanda's response was very short and not descriptive. Maybe this was too overwhelming for her to comprehend or remember. I just don't know.

I told Diane what Karen said to do about giving her the nighttime medications and she said "okay." So, I went in to the kitchen and prepared the nighttime medications with fear in my entire body. Is this it? Would she take this stuff and never wake up? My entire body was numb and then some. I think I sent Amanda to bed because I decided that if things went bad in the next hour or so I wanted her to be asleep and unaware of what was taking place.

I told Diane I loved her and I'd see her in the morning. She looked at me and tried to smile. All I could do was cry as I gave her the medications via the feeding tube. She was so strong. She wasn't crying, she was just staring up at me as she was lying in bed. In just a few minutes she was asleep.

I stayed up all night watching Diane sleep, thinking about what tomorrow might bring if she made it through the night. And even though all of this was happening, I just couldn't comprehend that this could be it. It was too

surreal. It wasn't possible. I believed (I think) that Diane would get through this crisis and we'd keep going on a while longer.

I remember watching her sleep that night and wondering just how she could deal with this thing that had happened to her. It was just two and a half years earlier that she was a healthy, walking, talking, and laughing super mom and super wife in the prime of her life. I thought about how each day, for the last two and a half years, she had lost her independence a little at a time. First, she limped from her left ankle going dead. Then her left leg became useless and her right leg grew weak. Then her left arm and hand, and then her right. It seemed like just yesterday when she started having breathing issues. And then she couldn't swallow anymore and her speech left her. All of this in just two and a half years. And through it all Diane remained the strongest of anyone around her. Diane never let on even to me how scared she was. As each crisis occurred she just rolled with the punches. When she saw me "freaking out" she'd just tell me what to do and everything was fine. I will never understand how she did what she did.

Diane made it through that Monday night rather well. We didn't even have a crisis that night. She slept right through. Tia came very early that morning, around 7am, I think. I went in to my studio and edited a TV show that had to air that night and called for a messenger service to pick up the tape around noon. I had asked Tia to come get me when Diane was fed and ready for me and her to talk.

I went in to the bedroom and sat next to her on the edge of the bed and Tia sat on the other side of her. When I walked in she gave me a little smile. Man, I loved that smile. I asked how she was and she said "okay" and then I asked her what she wanted to do. By this I meant "Did she still want to do the sedation?" She said "yes". I said "Honey, do you know what that means? Do you know what you are saying?" Again she said "yes".

I think we talked a little more about something else and then I asked again. She said "yes" she wanted hospice to come and sedate her. Again I asked her "are you sure this is what you want"? She said "yes" again. I then asked Tia to ask her. I wanted to make sure Diane was coherent mentally and really realized the impact of what she was saying. In true Diane fashion she got a little agitated and exasperated and said "yes", but a bit more emphatically. Tia and I had no doubt that Diane had made up her mind. This was the moment. Diane finally realized that it was time.

I have asked myself many times "how does someone come to a point in their life that they can make this decision?" How do you make the decision to end your life? For Diane, I guess she knew she had nothing left. She was exhausted and was on the brink of having a very violent end. I believe that this scared her more than dying itself. Plus, I know she was protecting Amanda and me. She was scared not only for herself but of Amanda and me seeing her choke or suffocate violently or maybe have a heart attack while having a life threatening episode. Even though I intellectually understand these thoughts, I am still in awe of how Diane was able to control this situation.

So after being asked three times about her wishes, Tia and I went in to action. By this I mean we did all the things Diane had instructed us to do if it came to being sedated. I called Amanda's school and asked them to find Janine Papin and have her call me. Amanda was on a field trip to, of all places, the Holocaust Museum. Since Janine was so close to Amanda, Diane and I felt that she would be the best one to get Amanda and bring her home. We didn't want Amanda driving knowing what was probably happening at home. As it turned out Janine brought Amanda and her kids and several other students with her. They all wanted to say goodbye to "Amanda's Mom." This was great and exactly what Diane needed and wanted. I called our good friend AnneMarie who came over and started making calls to those that Diane and I wanted to know what was happening. All day friends were dropping by.

Hospice people were coming and going and calling all day. Diane's parents started driving up from Miami. As it turned out they didn't get to the house until about an hour before the sedation started.

I was very busy that day getting things in order. Other than demanding that hospice bring a hospital bed for Diane I don't remember what else I did. I know I was busy doing things but I have blocked them out of my head. One time I went in to the bedroom and Diane was in the wheel chair making room for the hospice worker to set up the hospital bed. Around her were a half dozen friends along with Jana and Tia. She said to me "Where are you going to sleep?" I said "What? What do you mean?" She said she wanted to know where I was going to sleep if she was in the hospital bed. I said "honey don't worry about it. I'll just sleep on the floor next to you." Well I guess that wasn't good enough for her because as soon as I left the room she ordered Amanda and her friend to bring in the bottom section of the daybed.

When I walked back in to the room and saw the bed there next to the hospital bed I couldn't believe it. I looked at Diane and she just smiled. We had both agreed she would not die in our bed, but she still wanted to find a way for us to sleep together to the very end. "Amazing Lady" is all I can say about this.

Around 6pm Diane's girlfriends decided Diane needed "happy hour" one last time, and they fixed apple martinis. Now nurse Karen wasn't real happy about this, but realizing that "what the heck, what could it really hurt?" she okayed a couple of sips of apple martini. This was Diane's last party. She asked that the "boom box" be brought in and that "Tower of Power" CD be put on and turned up. Remember, Lee the trumpet player? Well he use to play for this band and this band was our favorite music group. When Diane was healthy and whenever this CD was played she'd dance, she'd sing and have a great time. I will always remember her dancing with my brother in the kitchen to this CD.

Around 7:30pm Diane asked what time it was. Her friends told her 7:30pm and she said turn the TV on. She wanted to watch "Wheel of Fortune" one last time. I came walking in and I can't believe it. Here it is one and a half hours before she is to be knocked out and she wants to watch one of her favorite TV shows! We all watched about fifteen minutes before turning it off. One by one, her friends went to her and said their goodbyes. I missed most of this. I was in the house but I guess I stayed away from this scene because I know I couldn't handle it. Diane did though. She was that "pillar of strength" as she always was.

Her parents arrived and immediately went to her side. They asked her if this is truly what she wanted. She told them "yes". They handled it quite well. Now I know why she so strongly demanded that we have that "sedation" meeting just twelve days earlier. I believe she knew it would come down to sedation and that she needed to know her parents would be understanding of her wishes. As always Diane was right in her judgment.

Amanda climbed in bed and we put Diane's arms around her. We all talked to her and told her how much we loved her and that we'd take care of each other for her. Seeing Amanda in her arms for the last time was truly the hardest thing I've ever had to witness.

It was 9pm when the sedation crisis team came in to the room and said it was time. Karen had just arrived because she had had to speak at a memorial service for a 9 year old boy who had died earlier in the week. Karen had taken care of this boy and had obviously grown close to him and to his family, just as she had with us. She did make it back in time to be there to say goodbye to Diane and to supervise the procedure.

Tia was also watching every move these new hospice people made. She was asking a lot of questions and making sure they knew what they were doing. I remember she was really getting upset when the crisis nurse was having a

little bit of trouble giving the medication in the feeding tube. She offered to do it but the nurse said she had to do it. That seemed crazy since Tia and I had been doing this for months now.

As they gave Diane the medications that would put her in to a deep sleep forever, I held her and kissed her. I spoke to her and told her how much I loved her. I told her how much I was going to miss sharing my life with her. I told her she was the best friend, wife and lover I could have ever hoped for. I told her she was the most fantastic Mom in the world and that all I had to do to be with her was to be with Amanda, for Diane lived inside of Amanda. I kissed her over and over and didn't want to let her go. I couldn't believe this was happening. My wife was going to go to sleep forever. What was going to happen to Amanda and me without Diane there to guide us?

Diane just listened and didn't say a word. Her eyes were filled with tears, as were mine. We just stared at each other like we had millions of times over the years. I can't imagine what she was thinking. I remember saying that this just wasn't fair. I felt so helpless that I couldn't fix her and this problem.

Within minutes Diane was asleep. I sat on the little bed next to her and a hospice "crisis care" nurse sat on the other side of Diane. Everyone left and said they'd be there by 7am the next morning. Karen had told me that Diane may be able to hear and understand me even though she may not be able to respond. So, I talked to her for a couple of hours. I just rambled on as I am quite able to do. I carried on a conversation with the crisis nurse for a while but I found her to be loud and not really appreciating where I was emotionally right then. Now I can't imagine being a crisis nurse but I have got to believe that they are trained to be more "in the background" during these stressful times. This lady wasn't. After a year and a half of wonderful hospice care this one nurse really didn't measure up. I should have asked her to leave the room as a few times when she got "loud" Diane reacted and was startled. Diane hated loud people in life and I'm sure she hated this. I decided to ignore her and lie down on the day bed.

I slept for an hour or so then got up, sat on my bed but laid most my body on Diane and held her hand. This is how we stayed the rest of the night. I'd talk to her and tell her things I remembered doing with her and Amanda or I'd tell her how much I loved her. During one of these moments I had an instant and totally random thought. I'd been having trouble coming up with the "perfect" person to sing at Diane's funeral. I had mentioned this to Diane several times. I had told her about this gentleman I had heard at a wedding a few years earlier who was a "Luther Vandross" style of singer. He had sung an edgy and powerful arrangement of "The Lord's Prayer" that knocked my socks off and I thought that Diane would really love this guy. But the bottom line was that there was no real connection to Diane and I really wanted someone special who knew Diane. She didn't really say one way or the other what she wanted. I guess that was the least of her concerns at the time.

Well anyway, I have this random thought that we might be able to get Michelle Amato (Yanni's Singer) to sing. I said this with lots of excitement and aloud to Diane. All of a sudden she opened her eyes, looked at me for about five seconds, raised her eyebrows once which meant "yes" and moaned at the same time. This was the last time Diane ever opened her eyes or communicated with anyone. I am so happy I was the last one she ever saw while alive. I had wished that her last vision would not be of some strange nurse, doctor or paramedic but that it was Amanda or me that she last laid her eyes on.

I can only assume that she was confirming my idea of asking Michelle Amato to sing for us when she raised her eyebrows. As it turned out Michelle sang a couple of songs at the funeral and was absolutely fantastic and the perfect choice.

The rest of the night was very peaceful. I may have dozed off a couple of times but I don't remember doing so. I just remember holding her and thinking this was the last time I would ever hold my wife, my lover and my best friend.

Around 7am everyone started to arrive. Karen, Tia and Diane's close friends. Kelly and Michelle brought bagels and tried to get me to eat. I wasn't hungry but to be nice I think I took a couple of bites and went back in to the bedroom. A new crisis nurse by the name of Seth came and would be there till the end. He seemed extremely knowledgeable and I felt confident in both Karen's and Seth's hands. But Tia was the "rock" for me and Amanda at this time. She never left Diane's side and was always conscious of Amanda and where she was. I must be honest and tell you I wasn't aware of Amanda during the next few hours. I probably should have been more aware because she was about to go through something she would remember for the rest of her life, but I was just trying to keep my wits about me while checking the medical people every step of the way. Plus I was forcing myself to stay aware and strong so I wouldn't collapse and be no good to Diane.

Since they were giving medications to Diane every two hours, the next dose was at 9am. Karen had said that Diane was responding very well and was in a very deep sleep. She also said she reached this point very fast. A lot of patients who are sedated take 3 to 4 days to get to the point that Diane had already reached. A few minutes after the 9am dose of medication she began to really slow down. Her breathing slowed and her heart was racing. Karen told me I might want to wake her parents up as this might be the time. I ran to the back bedroom and woke them up and told them to hurry to the bedroom.

After several minutes Diane perked back up a bit but not all the way back. The BiPap and Oxygen machines were working overtime. She just didn't have anything left for the machines to help her breathe. But, as she wanted it, she was out cold and in a very deep sleep and totally unaware.

At 10:45am Karen gave me her cell phone and told me that Dr. Jay wanted to speak to me. I took the phone outside and listened while he explained that in his opinion Diane was deeply under and was at the point that she wanted to be to end life. He then tried so hard to express how sorry he was that we were all about to lose Diane forever. Then he tried to tell me that it was time for the machines to be turned off. He couldn't get it out of his mouth. This man was professional and his compassion that day was monumental. He stuttered and stammered trying to tell me what was to come next but he couldn't say it, so I said it for him. I said "Dr. Jay I know what I have to do, Diane had talked about it many times and I know what she wanted and what has to be done." I then thanked him for the compassionate and superb job that he and the entire Hospice of the Comforter crew had done through the entire year and a half that Diane was under hospice care. With that I walked inside and said to Karen that it was time.

I had previously asked Tia to have a Bible open to the 23rd Psalm and to be prepared to read it after Diane passed. So when I went in I told her to get the Bible. Diane's parents and Amanda had left the room for a moment so I went in to the bedroom and locked the door. I had a brief discussion with Karen, Seth and Tia about what was to come next, and reminded them of Diane's wishes for this final moment. I then asked Karen and Seth to go into our master bathroom and close the door. Since the oxygen machine was a loud and very hot machine it was actually in the bathroom and connected to Diane's BiPap through a very long tube run in to the bedroom. I turned the machine off.

I asked Tia to stay with me and help remove the Velcro strap that held Diane's mouth shut. Diane had lost the ability to hold her mouth closed for the last few weeks. Tia removed it, said her goodbyes to Diane and joined Karen and Seth in the bathroom.

I was alone with Diane. I looked at her just lying there so quiet and peaceful but barely breathing. In fact, at this point, it was only the BiPap supplying her with air, and not very efficiently, since she could no longer receive it. Remember, the Bipap device is not a ventilator.

I held her and told her how much I loved her and was going to miss her. Then I took the air hose off her and for

the first time in months I got to see that pretty face. Even now, in this state, she was so beautiful. I kissed her hard and long and reached up and turned the BiPap off for the final time. Diane never took a breath. She just laid there ever so quiet. The ALS had finally won. All the motor neurons that were used for breathing were dead.

I then opened the door for the medical people. Diane and I had been very concerned that at the moment the machines were turned off she might have a convulsion or some reaction. We didn't want Amanda or her parents to see this so it was agreed that we would wait a few moments before letting them back in to the room. I could hear them outside the door, wondering what was happening inside and why we had closed the door. They hadn't realized that this was the moment until I asked Tia to open the door for them (once Karen assured me there would be no reaction from Diane).

Her parents came in along with Amanda and joined Tia and me around the bed. Each one of us were touching and holding Diane as her heart slowly began to slow. At some point I asked Tia to read the 23rd Psalm. As she read it she cried but somehow she made it through. By the time she finished, Karen pronounced Diane gone. I couldn't believe it. Intellectually, I knew what had happened but I couldn't believe my eyes, for here was my Diane lying there gone. I just stared at her for a while and cried. Again, I lost track of Amanda but later I found out that Tia had her under her wing. Thank heavens for Tia, for what an angel she was not only for Diane but for Amanda and me these last few months.

Some have asked how could I do this? How could I have turned the machines off? Actually, it wasn't that hard. I loved Diane more than life itself. I know she trusted no one as much as she trusted and loved me. I wasn't about to let anyone in this world touch her at this time. This was our time. This was what she had decided, and she made her wishes very clear to her doctors, parents, Amanda and to me. She knew the ALS was going to kill her. She just didn't want to die violently so she wanted to be knocked out, have the machines turned off and let the ALS do its thing. If she continued to live at this point, she'd do it without the machines. If not, she'd die peacefully. Her death was peaceful, and on her terms, in accordance with her decisions and her wishes.

Some have asked about the legalities of palliative sedation. What was the difference between what Dr. Kevorkian practices and sedation? Well, there is a big difference. Kevorkian devised methods for patients to commit suicide. Diane wanted to be put to sleep and the machines turned off and let the ALS do the rest. Hospice and I had suspected for a while that the BiPap machine had been keeping Diane alive for a couple of months, her lung muscles were growing less and less effective. Once she started to stop breathing even with the BiPap on, both she and we knew it was a matter of days or hours. Simply put, she didn't want to suffocate to death while awake. She just wanted to go to sleep.

After a short while I asked Karen to call the funeral home to come get Diane. Through the many months that I realized what was probably going to happen and how this scenario might play out, this was the time period that concerned me the most. I didn't want to see Diane lying there in our bedroom any longer than I had to, so I asked Karen to get the funeral home to come quickly. I understand that many families have loved ones lay there in the home for several hours. I couldn't do it. I knew I'd lose it if she was there too long.

I found things to do so I wasn't in the room for very long. One by one her friends came and paid their respects. Tia and some of Diane's girlfriends started organizing and getting rid of anything that was related to this illness. They did this upon my requests. I didn't want anything in that house that reminded me of ALS or death by the time they took Diane away. That came about one and a half hours later when the funeral home hearse came up the driveway. After about a half hour they drove away with Diane.

Several months before she died, Diane had informed me that she wanted a closed casket. I asked her if she was sure and she said “definitely.” She didn’t want her friends and especially her grandmother, Amanda and her parents remembering her as she was at the end of her battle with ALS. I understood and for several days I didn’t say a word about this, but it bothered me. This time period between her death and her burial really was hard for me, because I didn’t know where she was and what was happening to her body. I had taken care of Diane for 22 years and now someone else had her. This did, and still does bother me, but I realize this was the way it had to be. I did inquire from the funeral home as to where she was specifically. Anyway, after a few days I went back to Diane and told her that I needed to see her in the casket. She asked me “why”, and I told her I needed to know where she was. I also told her I would be the last one with her at the gravesite because there was no way I was going to walk away and leave her to a bunch of strange “gravediggers.” I would see her all the way. She laughed at me and told me I was “crazy” but I truly believe she felt better about all of this because she agreed, I was the only one to see her in the casket and the last to see her in the ground.

For many family members and friends this will be the first time that they know of this arrangement. Many people requested to see Diane but I explained to them that it was her request that no one see her. Diane wanted you to remember her full of life and laughter, not in a casket.

The night of visitation Tia picked me up early and we went to the funeral home. I gave them a locket that contained pictures of Amanda and me and asked that they put it around Diane’s neck. Then I went in to see her. Talk about having many conflicting feelings. I saw her but I didn’t see her. Her spirit was gone but her body was there. I talked to her but I truly felt that there was nothing there. I was only there for about five minutes before I went back to the lobby and just several minutes before her Miami family arrived.

Many friends came that night and paid their respects. The next day was the funeral at the same church where Diane, Amanda and I had tried just the week earlier to get to Sunday service. It’s been estimated that over 500 people attended the funeral. Diane made her entrance to a trumpet fanfare and then had friends and family members speak kind memorable words about her. I spoke of our love and life together and the many great times. At the end of the ceremony a 10 minute tribute video to Diane played. All the music was Diane singing and it showed photographs and video of the times in her life. When the service ended we traveled under police escort to the cemetery.

Hospice Chaplain Mike Caroline started his “gig,” as Diane called it, and was magnificent. He conducted the graveside service just as Diane had wanted it. Diane and I really liked the part where he asks people to yell out in a word or two about what they remember about Diane or best describes their relationship to her. Some people yelled out “great friend,” “loving Mother,” “Apple Martinis” and phrases like that. But then Diane’s father, Wayne, stood up and turned to the crowd and said that Diane was a fabulous entertainer with a beautiful singing voice and that the greatest salute to a great entertainer was a standing ovation. Everyone stood and applauded for quite some time. All I can remember was thinking “Oh how perfect, Wayne! Oh how right this is”.

At the end of the service, Mike asked everyone to go back to the house because I had asked to stay and have one last moment alone at the gravesite. I asked my angels Jana and Tia, along with Mike, to stay behind with me. Once everyone was gone, the cemetery people started lowering Diane in to the ground. As the casket is slowly lowered the cemetery representative asks me if I want the rose arrangement that is on to the casket. I say no, but then a few seconds later she says “Are you sure, maybe your daughter and Diane’s parents might want a rose?” I said “okay,” but by this time the top of the casket is level with the ground so Tia, Jana and I get down on our knees and start leaning in to the hole grabbing roses. We are laughing. We’re laughing because we all knew that if Diane could see us at that moment she’d be rolling on the ground with laughter and encouraging us to do something else totally crazy. It was a great memorable moment and helped give us all needed strength for the rest of the afternoon.

Grief

I thought that once all of this was over I'd get back on my feet, dive in to my work and try my best to raise my daughter alone and eventually be strong again. What, it should only take a couple of weeks right? Well, the day after the funeral was the lowest day of my life. Everyone, except my daughter Amanda, my brother Larry and my sister-in-law Shirley were gone. They were all great in trying to keep each others' spirits up, but I was hurting real bad. I wanted to just sleep and cry but I had to look strong for Amanda. In all honesty she was handling this situation much better than me.

For the next five days or so I was an emotional nutcase. Where was Tia? I began to realize just how emotionally dependant I had become on this young girl. For the last few months Diane and I hadn't made a move without her input. We trusted her judgment so much because we both knew we couldn't think rationally anymore. But now after 5 days I hadn't seen or heard from Tia. This wasn't like her. She was always there. But I knew I had to somehow stand on my own two feet and this dependence on Tia was not right. Some family members even started to believe I had romantic feelings for her. I guess it looked like that but it wasn't that way at all, it was total emotional dependence.

So around the sixth day I called her and got her voice mail. I left a message telling her I was worried about her and that I missed her. An hour or so later she called me back and we talked for quite a while. It seems she had crashed and burned as well. My hardest day was her hardest day. Basically, she closed herself up in her room and slept. Now I can't possibly explain this connection that I had and will always have with Tia. She shared one of life's most dramatic moments with Diane and I and she was an active participant in this moment of our life.

About three weeks before Diane died, I had come in to the room as Tia was tending to her. I stood at the end of the bed and just looked at my wife. I started crying because she looked so helpless and worn out. Diane saw me and asked me what was wrong, and I just shook my head. Somehow Tia started talking to Diane, saying all the things I was thinking. I can't even explain this moment. It was "uncanny" to say the least. Diane and I just stared at each other while Tia spoke the words neither one of us had the strength to say. Then it was over and we went back to what we were all doing. I'll never forget that moment. How did that happen? How did Tia know what to say and how to say it so eloquently and from the bottom of MY heart?

So after our long conversation on the phone I asked Tia to come over the next day. Amanda and I still needed her and we both knew she still needed us. Jana had been having some trouble handling Diane's passing, as well and she started hanging with us. This was good for all of us. Emotionally, I was hanging on like a string but at least the string hadn't broken. Tia, Jana as well as Zoloft and Xanax were keeping me together.

Grief is an incredible experience, especially if you were committed and truly in love with the one that you lose. I've lost a mom (at my age of 17) both sets of grandparents and close friends but the grief I felt and still feel for my wife is overwhelming. At this writing it has been 17 months since Diane's death. The heartache is still as strong as the day after the funeral. The only difference is that I somehow manage to handle it better most the time. Notice I say most the time, because there are still moments when I lose it and breakdown and cry like a baby. Maybe you can imagine what it has been like writing these memories. Reliving some of the experiences and writing them down to paper has cost me a couple boxes of tissues.

But letting it out and letting go is part of the rebound. If (and I hope you don't) you ever lose your true love and arrive here at this place called "grief," my suggestion is let it take you, but continue to fight it at the same time.

Yes, it brings me down, but when it does I repeat the instructions Diane gave me. She said “enjoy your life Keith. Live every moment like it’s your last. Take care of Amanda. Date, fall in love and marry again.”

I’m doing what Diane said. I am living my life to the fullest, as best I can, with what I have. I do things to enjoy my life each day. When I start feeling sorry for myself, I try to get my mind in the right place and not let the pressures of business bring me down to a place of frustration and anger. This is hard and I don’t always succeed, but at least now I recognize that place and try to right the wrong.

There have been those in my family who have been critical of my current decisions. I’m truly sorry they can’t grasp and understand what I DO UNDERSTAND. Losing a lover is different than losing a mother no matter how close you were. But we all have to deal with grief the best way we can.

As I embark on the rest of my life, I am excited to see what lies just around the corner. Professionally, I think I have finally figured out how to progress my business. Amanda is doing well and soon off to college. This will be hardest on me. She’s ready to start her independent life but I want her to stay with me forever. I worry about her all the time but do my best not to smother her. Not to worry, she won’t let me. She is her mother’s daughter, and like Diane, she is her own person with tons of spirit.

Diane has given me the greatest “goodbye” gift anyone could ever give a spouse. And that is “no strings attached” and complete freedom to live my life. She let me know from her heart that she wanted only great things for me, and most of all, for me to find love again and to share my life and my love with someone else. I intend to do that when the time is right, because what better way to honor Diane but to find a love like we had for each other. One thing I knew and always have known, Diane, “Nobody Loves Me Like You Do”.



*Diane, Keith, and Amanda LaMotte
- Christmas 2001*

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