

# *...lessons learned*

*Emerson T. Knowles*

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The cell phone kept ringing, one call after another – first Peggy’s sister, then her brother, then our daughter, no one could reach with her. Where was she? She was to be with her sister’s today. She was to plan her mother’s funeral. They were to pick out clothes for the casket and a myriad of unexpected, tough decisions but they would be there for each other. The three sisters were so different, but today they would be one. The last two days had been pretty rough. But with Marty’s passing this morning, we could now move forward.

...I had better head home and figure out what Peg was up to.

I walked through the front door and a scene of horror lay before me. Peggy was on the floor of our front hall having dragged herself naked through her own vomit from the bathroom. She was reaching with her right arm but her body would not follow. Her face was two images. The right looked at me, the left drooped as if to melt away. Her speech was frighteningly slurred. 911 was the call. She slurred out a protest, it would upset the neighbors. She had no idea what a horrific state she was in. And, for that matter, I did not understand it either. In the blink of an eye, Peggy’s life had changed in a way we could never imagine. I had only one focus – get her help and get it fast.

As I waited for the ambulance, I bent down over her on the floor and tried to figure out what to do. She had no clue that half her body did not work. I had no clue how to render aid. The ambulance was on the way. I got her bathrobe and put it over her. Our 21 year old daughter Libby calls, I tell her to come at once, something has happened to her mother, an ambulance is on the way – no questions, just come. A panicked child raced to her mother's side. The paramedics of Ladder Company Three rush through our front door. I have no recollection of time. It is a total complete blank.

The paramedics were the ultimate in both professionalism and courtesy. Did you fall ma'am? Can you feel this ma'am? We will cover you with this sheet ma'am? They were asking me questions, Peggy questions, I was so confused. I thought, get her to the hospital, hook her up to some IVs and she will get better. My mind just did not let me see how serious it was. The paramedics had been here maybe two or three minutes when they looked to one another, shared a thought and then went into high gear. We were moving fast to the ambulance. They understood the importance of time.

One of the paramedics wrote "stroke" on the sheet and showed it to me. He wanted me to understand but not upset Peg. I still had no clue, I did not understand. Marty, Peg's mom, had died of a stroke that morning. What does Marty's stroke have to do with this? As we rolled out the door and headed for the waiting ambulance the word stroke rolled around in my head with no meaning – at that moment, it was just a word. I was going through the motions, but as a man who prides himself on his intelligence, I am

sure there was very little functioning at that time. There were so many questions and I had so little idea what the hell to do. I ran with the gurney to the ambulance.

Peggy's mind was dying, second by second, before my eyes. The paramedics scrambled, the ambulance sped, the bumpy drive to the emergency room, our daughter rides silently in front – tears streaming down her face – terrified by the unknown. In back, a man who would be fascinated by this modern rolling doctor's office sees nothing but the horror in the deep blue eyes that peered back over the oxygen mask. The world was drowned out by the mind numbing siren, all fading into one single event that needed to end – and needed to end now.

In we rush, nurses fly, doctors talk, tests are taken. IVs, catheters and electrodes are attached, machines are beeping everywhere. There were doctors and nurses moving about busying away in a blur around us as I held my wife's hand trying to hold onto her life. Every 90 seconds she asked where we were, thrashing in fear of what she saw around her. Her eyes told the story of her inner horror. I spoke to her; she calmed... and then thrashed again as my calming words left her memory never to return. The ER may save your life, but it is a very cold and scary place.

How could we be back in the hospital? Only yesterday we were sitting vigil for Peggy's mother to die from a sudden stroke. I had just the day before told her 68 year old mother Marty, to leave her soul in God's hands. Early this morning her mother's last breath passed as she did. Do I say the same today to my wife as she lies drifting away in

front of me? I cannot, my wife cannot die today. How can a family loose a mother and sister on the same day? **My wife cannot die today!**

The doctor has said that a drug can be given and break up the clots – save her from the crippled state. The rule is three hours, but in her case it might be six. He will consult and return. The deadline is 6:00 PM or it is too late. I close my eyes to pray for his return.

I watch the clock. Time can be the cruelest companion. The hands keep moving, it is 5:20... then 5:30... the hands keep moving. I see my wife slipping further away. Where is the doctor?! The adrenaline is piercing every inch of my body. I can feel its crystal structure piercing my skin. No one appears. It is the worst time. It is brutal time. Panic overcomes me, I beg the nurses to call but their callous looks offer no comfort as they say I must wait as they tend to others and fill out their forms. How do you wait? As each second passes, my wife's mind is dying in front of me. With each passing second, death creeps closer. At last one nurse heeds my ever louder desperate calls and returns with the simple answer – it is too late, the time passed long ago. The Doctor went to dinner, he forgot to call. We are where we are. Time is a vicious thing. With each passing second; I watch my wife, the love of my life, fall further away.

In one second, in one minute, on one afternoon our world was incomprehensively changed.

I may have looked in control on the outside but I was totally disoriented on the inside. It was like the movies but way too real! My father had been a professor at the medical school. I had grown up in a world of doctors and knew many of the most prominent and connected in town and it never occurred to me to call a single one of them. Whatever common sense I normally possessed had been wrung out of me by an overload of adrenalin so severe that it hurt.

It was the nurse that finely explained to me what was going on. The EMTs had tried, but I was not ready to listen. *Stroke* had just been a word, then it became something serious, now it was a brutally sobering reality. Peggy had experienced a crippling stroke. Even if life makes it through the day, it will never be the same for Peggy again. It will never be the same for any of us. Peggy struggled to get out of bed and asked to go home, we would explain to her she had a stroke and was in the hospital. She would accept the explanation and relax. Then, a moment later, she would thrash about and ask again, then again and again. No matter what you told her, a minute later it was gone. The doctor had recommended we strap her down. That was not going to happen to her. It did not happen to her. I could not imagine that this would be Peggy's future! It became viciously clear, we are going to be here for a while, a very long while.

Decisions, decisions, so many decisions... I think I did an OK job. But I needed someone to be there with her to help me see, to help me understand. We all know the patient needs an advocate, but when it is so close that you are overwhelmed, you need an

advocate too. *The first lesson learned* – ask for help and don't think you can do it alone, because you can't!

As I sat beside Peg's bed holding her hand, praying for her life, I remember almost nothing. But I do remember the clarity of purpose that started that night. It was to bring her back. I had no clue how. But, it did not matter. The love of my life looked to me with mix of terror, confusion and hope that said it all. I had a life to save – and nothing else mattered. *Another lesson learned* – when the true crises hits, you forget the little stuff – you don't care about the little stuff.

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At some point, we moved to the Neuro-Intensive Care Unit. It was a small, one person room full of all the right equipment to monitor the very sick. To this day, I recall nothing of how we got there.

One by one more of Peggy's large loving family began to come in and out and help with her care. Just like me, they had all taken the week off for Marty's funeral. It gave me the time I needed to try to deal with the enormity of this. She lay there paralyzed, tubes all over, a gown designed by a sadist, sheets like sandpaper that bloodied her elbows with her sense of self, dignity and independence totally stripped away. I wanted to protect her from this horrific scene but I did not know how.

Through all this turmoil, the flowers and cards began to pile in. There were so many flowers that you could smell them when you stepped from the elevator. They began to consume the room. Every couple of hours another cart of flowers would come by and would be unloaded into Peggy's room. We were feeling overwhelmed with the outpouring of love and support.

The staff was getting annoyed. Our hot and cold running family along with a room full of flowers was getting on their nerves. I was informed this was the Neuro-ICU, not the family ward. I had now been up for about two days straight and I am sure my personality was atrocious. I vaguely remember the stupidest conversation, well ridiculous confrontation, with the head nurse who demanded we get rid of the flowers; they were in the way! *Another lesson learned* – when you are a stressed out, over tired lunatic, have someone advocate for you who has a calm head. No one should come to words over flowers. Later, a cool headed friend stopped by and spoke to the nurse for me, the flowers stayed and we moved to a new room.

Somewhere in the middle of this, I reconnected with our younger daughter in Colorado. We had not spoken in months. We had been distant for years. Whatever barriers we needed to overcome from our difficult times would need to be overcome right now. A healing that would have taken years, took place today. In a tearful call, Courtney, then 19, pleaded to come home. I wanted her home; I needed her home. Past words melted away and a new lifelong relationship began. The tickets were purchased

and our daughter was on the way home. A new foundation of trust was started that is unshakable to this day. *Another lesson learned* – stuff your pride in a sack and reach out to those you love. In a crisis, pride does not matter and past words cannot matter.

With the confidence of family by her side, I ran to the house to discover 22 phone messages of support. The list grew with each day as the calls poured in. I wrote down name after name, so many wonderful people standing behind us. The small gestures of a card, flowers, calls from so many, made the world change for us.

The scene at our home was sickening. The patch of vomit she had dragged herself through had dried into the carpet and it truly reeked. On my way out, I handed the house keys off to our condo manager and explained I could not come back to this again. We had never given our keys to anyone. This would be the first of many times I would have put trust in those I did not know. To this day, I have never been disappointed. *Another lesson learned* – when you are in great need you must grant trust in those around you and people will rise to accept it.

Have you ever noticed how comfortable waiting rooms chairs are? It seems no matter how you sit it them they just don't fit you. You move forward, back, sideways... it does not matter. Somehow, I'm convinced they were never actually designed to be sat in. Well, after several days of stress and sleeping in those chairs, I developed a massive case of hemorrhoids. As word spread among the family, when each member arrived they would look and say "What a pain in the ass," and laugh. It broke a layer of tired ice that

needed to be broken. *Another lesson learned* - a little humor goes a long way in a tough situation.

We had been in the hospital for 10 days now. Life had been preserved, the doctors had done their magic and rehab was in our future. The flowers, the cards, the calls, the support... It had overwhelmed us. How could I thank them all? They needed to know what a great thing they had done. Our lives had changed; but also enriched in ways we could not imagine. The bright light from their decency had blinded us.

The only way I could figure was to send out an e-mail. A little cold, but it was the best I could do. After 10 days of relentless challenge, shortly after mid-night an exhausted 46 year old sat down and pounded out a note. A note drawn from raw emotion he never knew he had. An excerpt:

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It is often said that life is precious and nothing should be taken for granted. I never understood the importance of this simple line. Then I learned about the tragedy of a stroke. I thought it was just for octogenarians with health issues. I could not have been more wrong. I never understood the impact just one single second could make on the rest of your life. A stroke is like an earthquake. There is no warning, no sign to see it coming, in one single instant a part of your world that you thought was secure comes crumbling down.

Such paralyzing tragedies are not supposed to befall healthy, energetic, loving 45 year olds. Let alone just six hours after their healthy, energetic and loving mother dies of a sudden unexpected brain hemorrhage. This week could have been a week from hell. It could be wrapped in tears of despair, but with all the challenges it presented it was not. Your flood of support has made a difference that no language on earth can describe.

Peggy's hospital room looks like a florist shop, the cards, the letters, the calls, the colorful pictures from many of our 34 nieces and nephews, the messages, the e-mails, the food, the visits, the offers to help.... Every time we look around our room we are overwhelmed, every time someone calls and we try to explain this we are overwhelmed, every time we think of how blessed we are to have you as friends we are overwhelmed.

This has been a week for tears, but most of our tears are drawn from the wonder of an overpowering support that gives you the strength to advance on any challenge. The rehabilitation process is a long tough road that has no clear cut map. Peg has an excellent start, her spirits are high, and her humor is positive and forward looking. Her road to recovery has jumpstarted beyond our greatest hopes. Only God knows what will come next.

I hope and pray to have Peg home from the hospital before the month is over.

I hope and pray she will once again be able to take for granted walking, talking and seeing the world as we do. The mountain we are about to climb will be tall and uncertain, but with the strength we have drawn from the love, support and prayers we have received from so many, we will face it with solid hearts and unclouded minds. The hope that carries us through each day is a gift for which there is no thank you that can ever do the job. I carry a debt of gratitude for which there is no lifetime long enough to repay.

The strength you have given us has made all the difference. Her progress, her attitude, her drive are the living proof of that. Her recovery will be faster because of you.

In your debt forever,

Emerson

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The next day, close to a hundred people received this note. Several of you sit before me tonight. *Another lesson learned* – let people know what a difference they have made for you in the face of tragedy. Let them know how important they are.

The paramedics and Doctors saved Peggy's life. Now it is time for the therapists to teach us how to take care of ourselves again. I had no idea what it will take get her life

back, but with the support of so many, I know we will get there. We have so much to learn.

I met the hospital staff and they reviewed their program. It was a massive list consisting of four to six hours a day, five days a week. It would be weeks of grueling work just to learn to put on a shirt. During that conversation, I kept thinking about her, lying in bed, her left side dormant hardly able to lift her head.

Peggy was forgetful, constantly exhausted, blind to the left and forgot everything that fell out of sight. The doctor explained that if she were cooking and turned away from the stove, she would no longer know or remember there was a pot on a burner. She could either burn the house down or turn back and put her hand in the fire. She would only know the latter when she smelled her own burning flesh. The doctor made it very clear that Peggy should never be alone again, probably never walk again, read again, write again and many other things we so much take for granted.

I had no idea how, but this was not going to be her fate

After this most daunting of forecasts, a woman with a limp, a cane and a story to tell walked into our room. She talked of lying dormant with no idea what the future would hold; how she could not walk for months, how her speech was so awful and how she dribbled food when she ate. And yet, she sat before us with a calm and loving confidence in her eyes that said it all. It was the most powerful of days for us. To this day, we don't know who she was or where she came from, but she showed us a future that can be ours –

that will be ours. ***Another lesson learned*** – When you see that it can be done, hope becomes certainty. And, certainty knows no limits. It was the most powerful of days.

I kept a list of all those who called and lined them up for visits, one visit at lunch and one at dinner. I then taped a page from a monthly desk calendar on the wall of the room. Each time a guest came to visit, I would have them sign up for their next visit a few weeks out. Being with friends was normal. Since we could not go to normal, I had normal come to us. ***Another lesson learned*** – take advantage of *everyone* who says “if there is anything I can do...” When they say it, write it down and ask them to help. My father used to say the old English proverb “many hands make for light work.” This is a time to *live* that proverb.

As the days rolled by, these visits proved an elixir for continued effort that I never imagined but we so desperately needed. As a friend would come for a visit after a long break, they would walk in the door, see the progress and light up like a Christmas tree. That sincere, from the heart outburst of enthusiasm was the fuel for another day of effort we needed so badly. When Peggy faced hours of exhausting work ahead, that fear and pain disappeared into the unabashed enthusiasm of our guests. It laid a precedent for positive effort and improvement that is part of our home to this very day. ***Another lesson learned*** – Surround yourself with loving, positive support and the job becomes exponentially easier.

Forty seven days later, we were getting ready to go home; it was a day of joy and a day of sobering reality. Our future would now be ours and we had no clue how to cope. Most families with this type of catastrophe go bankrupt, most marriages fail, many live alone and isolated. Many will carry the emotional scars from the event for years if not forever.

This will not be Peg's future; this will not be *our* future.

When we come home it will be the start of our new lives! I cannot share enough what this meant for Peggy. She wanted out of the hospital so badly she would cry about it; she would literally shake with joy at the prospect of going home. Her own bed, her own clothes, her own food, it was a dream come true for her. With each passing day, Peg needed less care. At the same time, my ability to cope was rising. With some adaptations to the house and the hiring of care-givers, I would be able to handle it. But, it was a daunting thought for me. The hospital, as cold and bureaucratic as it was, took care of many, many things. Now, I would take care of all those things. As I signed the papers that I would never leave her alone for the rest of her life, be responsible for getting her therapy, pay all the "un-covered" bills, get a five year "disability hang-tag" for the car and who knows what else, it was a very sobering moment.

With an open heart, relentless conviction and smothered by the prayers of many we stand on our unbending hope for a new tomorrow. It was time to take the reigns of our own future. There are no martyrs here, we are marathoners and the long haul is ours!

Friday, May 16, 2003, Peggy, a mountain of family photos, children's drawings, cards, flowers, a wheelchair, a four point cane and several carloads of other accumulated stuff headed home.

It did not take long to figure out how complicated coming home was. Up two and three times a night, managing therapies, drivers, visits, caregivers, a full time job and a mountain of other things. No wonder so many are overwhelmed. It was clear to me we had to run this just like the business. So off to the office supply store and home again with six foot calendars, white boards, time charts and lots of colored markers. Therapy in Red, visits in Blue, rest time in Green, caregivers in Black... it was an ever overlapping fabric of color that kept our house running instead of falling apart. ***Another lesson learned*** – running a recovery is just like running a small business. It is a simple combination of drive and logistics, *lots of logistics*.

As complicated as it was, it was good to be home. Now it was time to get our lives back. As I looked over the intricate landscape of our new life, one thing was very clear – the mechanics of our life had changed. But our life cannot change. So what is normal? Friends for dinner, out to a show, vacation with family... all the things we do that give us that wonderful sense of friendship and connection needed to be ours. As I looked at my wife sitting in her wheelchair, I understood that the engineer in me was about to get a real challenge – but a damn worthy challenge.

***“Never confuse a physical challenge with a barrier to your dreams”***

Our family maxim then, our family maxim now...

We were ready to charge forward, but our stint away from the hospital only lasted two weeks and back to the emergency room we went. When driving to a family wedding I realized one of Peg's legs was bigger than the other. Peggy had a blood clot – a three and a half clot from heel to chest. Flat on her back for weeks and back in the hospital unless I give her shots. I did not even need to ask; I took the syringes and we headed home. I gave her the shots.

Now flat on her back for the summer it was time to figure out normal again. Lookout living room, here we come. With the help of friends we picked up much of the living room furniture and piled on the side of the room. In its place we put a recliner, rolling tables and a ring of chairs. Each day Peg would make her way to her chair, raise her leg into the air and life went on. Therapy worked from the chair. Visits were made from the chair. Dinner parties were wrapped around the chair. Life wrapped around the chair. Our beautiful designer home was a wreck, but life was full. *Another lesson learned* – what we had did not matter, what brought us life mattered.

Our family vacation was to be a real challenge. How do I get Peg from Cincinnati to Walloon Lake flat on her back without further risk of blood clots? I needed a car with a recliner built in. And, Warren and Chris Allen offered their giant SUV to make it so. A center captain's chair fully reclined, two coolers to create height and a pile of sleeping bags later Peg was safely reclined in the back of the giant car. We stopped every hour so

Peggy could take a walk and insure her safety. We have to be the only family in modern history to take three days to drive from Cincinnati to Michigan. But, we did and we joined our large loving family – just like normal people do. That simple act of kindness from Chris and Warren let us enjoy a normal family vacation. What a difference it made.

We had been on our own for about two and half months now, and much of the new mechanics of wheelchairs, ramps and all the rest were becoming our new normal. We no longer thought about many of them, we just lived. While sitting at dinner in Michigan, a scene unfolded in front of me that let me know we were on the way home. It was the first time I relaxed in months. I share part of a letter I wrote the next day.

“Last night eleven members of our family came together for a nice evening out and as I looked to the other end of the table I saw someone relishing the conversation, enjoying the fun and laughter a close family can bring, cracking jokes and enjoying her evening just like she always did. There is no greater peace or pleasure I can have than to see her engrossed with the depth of life and all her challenges so far away. We were having a normal evening! Not just a normal evening but all the steps to get there are now becoming natural enough that it is no longer a stress driven effort to get out, get things done – or just get through the day.”

Somehow the fear was gone, the uncertainty was gone. So many new lessons learned that I could now see a new and wonderful normal.

We followed this trip with a business conference at the Breakers later that fall and learned a whole new set of lessons about old hotels. But we figured it out and had a great time. Later in the trip, Peggy and I had dinner with our CEO, Tom Matthews. In a gesture of kindness, Tom seated us with Leo Thorness, recipient of the Congressional Medal Honor and former POW. Tom felt that Leo, who had spent six years in brutal captivity, would have special insight for Peg. Tom's logic was that Leo was in a prison cell, Peg was trapped in her own body and both required long, arduous recoveries. Tom could not have been more right. Leo's support and understanding helped drive Peg to new levels of recovery we never believed possible and led us to our new home in Arizona. A simple act of kindness from Tom opened a door for our future for a new home and a new life. He will never understand the impact of his small act of kindness.

A year after Peg's stroke, I was diagnosed with cancer. Four hours of surgery later, I woke up in a hospital bed with a new nine inch zipper across my abdomen, a multitude of tubes, machines and a catheter. As the anesthetic wore off, I can only imagine what Peg felt like just a year ago. I was so dependent on everyone around me. I was so vulnerable, so helpless – and I knew it would go away. It opened a door into her fear, her challenge and for me an immortal respect for the courage she had to fight for her recovery. I hope I could be that strong of a man. When I landed home, the recliner was back in the living room, this time for me. My children were now caring for me, just like we had their mother.

After three days of being helped everywhere I had enough, I was getting up out of that chair by myself. So, I told my 20-year old daughter Courtney to stand back, I was getting up. I pushed the leaver to upright the chair and closed the footrest to get up. Courtney stares me down with a parent's voice and says "Dad, don't get up". I think, *what the hell is this?* Courtney is using the "parent's voice" on me, no way. As I ignore her, she steps forward and places her hands on my chest and says "NO". My eyes glair back and she says with a cool look "Dad, look down". I had closed the footrest on my catheter. I was about to redefine getting my chain pulled. ***Another lesson learned*** – It was hard for me to "listen" to my children when they needed to parent me. I now know how hard it is for them and their mother.

We have learned so many lessons and had so many more to learn...

We put together a stroke team for the heart mini marathon and hoped to get 25 and raise a thousand dollars. 150 supports later, we raised 25. Three years later we raised 75.

The letters of support that got us through the day  
People holding doors while we lumbered on our way  
The friends who took Peg out so I could have a day  
Respite at the Lit Club so I could find my way  
The list is endless...

Through all the stress and all the challenge, a life lesson was being born that we carry to this day. The little touches from so many made a time of wonder not of pain.

Yes, pain was there. Yes, fear was there. Yes, an uncertain future hung over us. But this potential nightmare was swept aside by the loving touch of the thousand hands that carried us forward each minute of each day.

We knew our future was bright, because we had the privilege of seeing the true brilliance of the human spirit in that continuous stream of kindness. The ideal summer day may bring you a special warmth, but the intensity from the love of our fellow man will touch your soul. With the strength from so many, I knew we would have a bright tomorrow. Give yourself faith in the inner strength we were created with and the miracle takes care of itself.

The road map for survival then and the road back to normal now has no guide book. It is a “learn as you go” process. Our road is full of *lessons learned* and in our story I have documented close to 100 of them. Tonight, I have the privilege of sharing just 14 with you – about 38 minutes worth. Through all the challenges and changes that have brought us back to a full and engaged life, there is one lesson that stands above all others:

***“Never underestimate the impact of a small act of kindness”***

Take the 30 seconds at the store to pick up a card, contact a florist, meet a friend in the hospital instead of a restaurant, offer to drive, write a note, make a call, the list is

endless. That five minutes in your busy day is a message of caring and hope to those in crisis that will make a difference for a lifetime.

Peggy is still paralyzed on one side, still forgets things and is still almost blind. Travel is still a pain, routines are a nuisance and everything we do just takes a whole lot longer -- but it does not matter. We have the gift of seeing the true decency of man that is so shrouded by the mind numbing pace of modern life. We live each day with full hearts and clear minds drawn from the strength, caring and prayers of so many.

We have seen the power of that small act of kindness and we pray that all of you can share in this *greatest of lessons learned*.