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THE TERMINAL BRAIN ILLNESS OF MITCH AND JB

JB AND HIS SON:

IT WAS NOT LONG AGO SINCE-I WISHED THAT THIS WAS ME

It was not long ago since I hugged Mitch, kissed him and said; “Good bye Mitch for now, my son”. It was not long ago since Mitch Soul, while between my arms, was taken from our house on earth to the house of our Heavenly Father. It was not long ago since I was by Mitch side and did not leave him while going through the painful and exhausting chemotherapy treatments. They were administered through an access port that was placed close to his shoulder. The port provided an access for the concentrated chemotherapy to go directly to the heart without damaging his veins from its toxicity. My son suffered from a brain tumor when he was 6 years old and survived for nine and half months before he expired. He touched every one. He always had a smile and aura around his angelic face. He was glamorous and was exactly like his dad.

It was only eleven years ago when Mitch departed. Neither I nor his mommy or siblings wanted him to go. But he wished to go to be by the Heavenly Father away from the illness and suffering on earth. The three sisters (10, 4 and 2 years old) were by his side. The two other brothers were not born yet. They are now 8 and 6 years old. I will tell you everything about them when I see you face-to-face, my son. I will not let you go from my hands once I put my eyes on you. He was my oldest son and three years younger than my oldest daughter.

All of sudden, his time had arrived. His soul was taken from our hands and flew up high with the heavenly angels but he remained with us. Mom and I hung his picture by our side. He is present with all of us. I look at his picture every morning and see his angelic face. His photo was framed and was hung next to a picture of an angel. We called him; “our angel Mitch”. Whenever, I am about to

do a project, I would call the name of our Lord and our son Mitch. Our life continued with his spiritual presence.

It was not long ago since Hospice came to our house to comfort him at the end of his illness journey on earth. My son had suffered through the illness. Medicine and science could not save him or dare to stand against the Creator will. While my hands were tied, I felt helpless, cried and looked up to heaven; "I wished that this was me instead of you". It was only nine years later when I learned that I have what you had my son; a brain tumor. I was already inspired by you and we are both again together. I felt him every step of the way. I followed your footsteps. My son had sent me his other angelic friends from heaven to be with me as he always did with others when he was in our physical planet the earth. Today, eleven years later, he would have been eighteen years old, my angel Mitch.

It was not long ago since Hospice came to comfort my father in law on his death bed in Florida. It is my time now. Hospice is here in our house in Illinois to comfort me in my last days on earth. I am ready. I want to see my son. I want to say how much we all loved you. I will give him a special hug to you from his mother and siblings. It has been a long journey for me. I had two brain surgeries, one in the left and the other in the right. I had two long session of radiation and many days of chemotherapy. The brain tumor is growing like that of my son and is taking me from his mom, three sisters, two brother and all the loyal friends.

Mommy will be by herself. I pray to my God to be by the side of my family. I will leave but I know I will be always with you. I am blessed, my son, look to how many blessings and how many friends. Even in my last days, my neighbor did not forget about me, the home made meals are coming and coming. We have abundance of more than we need. He had many friends and for two years every one was racing to help out in any way, form or shape. What should I say to the friends and the community; "Thank you for what you have done for me and my family. You have not let me be in need of anything. Thank you"

THE DOLPHIN STORY: THE SIGN FROM GOD AND MITCH

Mitch did like dolphins. Whenever the parents wished for Mitch to smile, they will bring the view of a dolphin. In fact, if a dolphin name was mentioned to him, he would stop crying and look for it. The Dolphin was one of the ways that eased Mitch's pain and suffering. In the depth of his cry, the dolphin brought hope and comfort to Mitch. His father believed strongly that, even though Mitch passed away, he is still with him. Mitch was the angel to the entire family. Anytime, Mitch name was mentioned, special memories would come to each mem-

ber of the family. It is of great admiration to see the six years old child who suffered from a terminal brain cancer and died at the age of 6, have such a memory and respect to many people, young and old.

As soon as, JB knew he had a brain tumor, he and his wife called for God and Mitch. The first hospital had no brain surgeon. They had to go to find a hospital. Two hospitals were known to them; one where the daughter worked and the other closer to home. The wife was driving the car. She was getting repeatedly lost. It was an emotional shock. She called for directions. She continued to get lost. At some point, she made it to a third hospital. They drove around and found a beautiful fountain with two dolphins. Immediately, they felt the spirit of dolphin and the God will for JB to be treated in the third hospital; "The hospital with Dolphins". Sure enough, once he entered the hospital, planned work up was organized and done within an a hour of admission. The entire family felt the blessing of God and Mitch hands. JB rested from an exhausted night. His neurosurgeon came and talked with him and his family with the finding. The family noticed a golden chain around his neck carrying the cross of Jesus, Jesus face and the Virgin Mother of God Saint Mary. It was their second message of God that He was with them. They believed that this where God wanted him to be. It became a tight association between Ghaly and the patient and his family for almost 22 months of the entire illness journey of JB.

THE HOUSE OF THE TWO VICTORIOUS ANGELS

The house of JB has two angels. I got to see the traditional hospitality with its generosity. The doors of the house were wide open for coming and going. The arms were welcoming many visitors, friends as well as strangers. I immediately felt that I was one of the members of the house. The hands took me around. When you are in the house, you immediately get the impression with the presence of God Spirit and the hosts of angels. Next, you get to see three magnified pictures of Mitch, one on the entrance, the second on the dinning room, and the third on the second floor. I was introduced to him. It was really emotional. Soon, there will be an additional victorious angel, the dad himself. One day, both were living in the house and passed through the earthly tribulation and suffering including the illness journey that was placed before them. On another day, both were gone from the house and became the invisible angels of that house. They are the household advocate before the Lord. They intercede for the living house members. What a fortunate house to have two faithful servants before the Lord! They both carried their cross to the last drop of their blood and to the last breathe of their life. They indeed endured to the end. Now they are comforted in the Par-

adise of saints. Do not fear anymore O'h household because God and His angels are with you. One day, both were our friends and in another day, both are our angels and advocate in heaven. What a thoughtful view!

THREE WITH BRAIN TUMORS IN THE FAMILY

The brain illness in the family affected first Mitch the 5 years old child. It was 1995 when the family learned about Mitch terminal brain journey. It took his life when he was 6 years old. It was cancerous and inoperable. In 2001, the mother learned about her brain tumor that caused almost fatal hemorrhage. She was transferred to major university medical center and had to be taken to surgery immediately. It took long suffering before she recovered and went back to work. Her speech was affected. She was told she had a benign brain vessel tumor and serial MRI was needed. On 2005, the father, JB, learned about his brain tumor. Like Mitch, it was cancerous and terminal. It was far more serious than his son Mitch. It is incredible to see this family going through one of the worst brain illnesses. They are deadly brain sickness. There was no rest time; by the time one was done, the other was to follow. With all these deadly events, there was no moment of anger or losing hope. "Never, I have seen a family go through what this family has went through!" said Ghaly and the rest of the community. The strong faith did not depart from their house.

THE THREE CROSSES

Ghaly went to Saint Anthony Monastery, in Yermo, California. He met a Coptic Orthodox Bishop, his grace Bishop Sarabamon. Bishop Sarabmon had given Ghaly several hand made crosses with the monks' prayers. In one of JB clinic visits, a cross was handed and he put it on around his neck. He kept the cross close to his heart. Two other crossed were handed and his youngest sons put them around their neck. The sons were as angelic as Mitch was. The three crosses almost resembling the three crosses that the family was carrying. It was humbling to see the effect of Jesus Cross on the family. They are indeed carrying three heavy crosses, Mitch, JB and the wife. Although the crosses were heavy burden, they were light in weight and joyful to carry. It is because the Lord Jesus was carrying them in their behalf. They have never questioned the cross. For them, it was a gift to bring them all closer to the Almighty in unity.

He liked very much the clinic. In one of his last visits to Ghaly clinic, he said; "I prayed to God to give me more chances to come and visit with you in this office. We love you so much. We like to come here" He admired the Christian Icons and the peaceful scenery in the office. He loved the framed patient stories

that were on the wall. He always came with his wife and genuinely asked about the well being of Dr. Ghaly and the practice. He came and patiently waited. The clinic visit often lasted 2 hours.

JB LIFE STORY

I was born in a small city named Mishappan, Pennsylvania from wonderful parents. My parents were my friends and exemplary model. I learned many things from them. I was raised with two other brothers. I left Pennsylvania and came to my destiny place that God had chosen for me, Batavia, Illinois. It was an area that had no development. Yet, I have built many homes and remodeled many more. I witnessed the growth in the community. The hand of God was with us. We went together to church. The schools are by our doors. The six children are successful in their schools. My oldest daughter is about to graduate to be a nurse and help many patients like me and you. I pray for my family. I came from a healthy family. There was no history of brain tumor or cancer. My other siblings are living well as well as my parents. I was very healthy and active

THE JOURNEY OF TERMINAL BRAIN CANCER; THE STORY OF THE BLIND FAITH AWAITING FOR THE DEPARTURE TIME BUT I WILL NEVER GIVE UP

The illness started with some headache on September, 2005. He was told that it was stress. The headache got worse; he was told to see a psychiatrist. It was depression. He went to the psychiatrist. Medication was given but made him awake and irritable. The sister-in-law living in Florida close to the water was organizing for the entire family to move and live close to the beach. His parents were also living in Florida. In the mean time, the headache got worse. He started to see flashing in his eyes. The man continued to suffer and be tolerant to the headache until January of 2006. He called and a CTScan of the brain was arranged. On that day, the wife's mind believed that; "there is a big problem with my husband brain". The CTScan results indicated a brain tumor. He was moved to another hospital, "The hospital with the Dolphin". The MRI of the brain revealed three large tumors with dangerous brain swelling. The tumor was multi-lobulated and located on three different locations. One on the left side, the second was deeper to it and the third was in the middle. It looked cancerous and inoperable. Surprisingly, he was doing well except for some headache to develop to a terminal brain cancer. Medications were administered intravenously to decrease the brain swelling for the time being.

MIRACLES CONTINUED WITH JB

The traditional teaching is to administer only palliative and comfort treatment. It is cancerous and terminal. There is no sense to let him go through surgery and “Heroic measures.” Ghaly informed the family that;” Doing nothing would bring death on less than a month. On the other hand doing everything, may prolong life for few months”. The headache was severe and the pressure inside the brain was high. Some would have done no surgery and let him die without going through the experience of surgery and its complications. He was not one of them. He would never give-up. His life would have been only few weeks if he selected no treatment. The name of this medical route is ‘comfort care’. He has 5 kids and wife. He was not ready. The surgery would only take two out of the three lesions. It would make the diagnosis by looking at the tumor tissue by the microscope (Pathology slides) and decrease the swelling so that the healthy brain would have a room to breathe since the skull would not give in and stretch. The surgery was done and the kids and his wife were around him in the hospital room. His parents and friends were also around. He made remarkable recovery. He was discharged from the hospital in four days. He was a champion going in and out of surgery.

The pathology report was confusing initially. It was thought that it was a cancer coming from somewhere else. It looked so aggressive and matched other cancer types. Many imaging examinations of the entire body were done. He had to see other specialists. It was a difficult time since he came to know about the brain cancer. Nonetheless, the final report came back as the most aggressive type of brain tumor that had originated from the brain. The news was depressing. But he did not give up; he wished to fight the battle that was before him. He accepted the facts and made the best out of the grizzly news. Anyone that had looked at him, would never know that he was carrying a terminal illness above his shoulders. The 6 weeks of radiation, 5 days per week session passed smoothly. He received long term chemotherapy by mouth.. No side effects, his body helped him. His daily prayer had been by his side. He continued to be around his family doing well for a year and celebrated his forty eighth birthday. An MRI was done every two to three months. He accommodated the plan of care and medical recommendation literally. Things were miraculously quite. The concern arose all along with the kids’ reaction to everything they had been through. Psychological assistance was provided by the consultants as well as the church ministers. The middle lesion was getting smaller and no swelling. Statistics said he only should live 9 months with poor function. The daily church prayers that were raised for

him was reaching the merciful hand of God. Ghaly was preparing him and his family for the departure time. He would come with his wife to Dr. Ghaly office to go over the MRI results. He would look apprehensive, yet he would not lose his smile and faith. As if he had already known the good results.

FLYING IN THE AIR: I LOVED HER EVEN MORE

His wife worked for Domestic Airlines. The couple had never enjoyed time together as much as they did after the first surgery. The brain cancer event had put them closer than ever before. They loved each other more and more. Many vacation trips to different States within United States were made. The couple was vacationing from coast to coast, from a flight to another and from a drive to another. There was no time to waste. He liked Dining with his friends and family. His love for his wife grew even more. No matter where they go, they go together. You could not talk to one and not the other. His wife forget to take her seizure medication, he took her to the Emergency Room and let her see Dr. Ghaly. He got her records from another hospital. She had a brain surgery on the left side for benign vessel tumor. Her good news was the blood vessel tumor was gone and would never come back. She needed to be always on seizure medication, otherwise she would have seizures and would not speak. Amazing, he was able to know exactly what was going on with his wife. Both parents and the son had brain illness. The brain illness put them all together. He was conversant and cared about others and was content with his news. They used every minute of their time to spend the best they could. They knew tomorrow “may never come”. Yet, the kids were going into their daily adventure as if their dad will be living for ever. Nonetheless, the older one knew the fact of the terminal brain cancer of their dad. They were together, all the way to the end. The family was one in great loving unity.

A YEAR LATER

Exactly a year later, the tumors were growing fast. He knew things are not looking favorable, yet he continued with the blind faith and no hesitation. He would worry about his wife and kids more than himself. In fact, he would not say what bothered him in order not make an additional load on his family. His family dynamics were going as if nothing was really occurring. The kids were going to school and doing well. He was the loving dad and husband. His image continued to be the man of the family. Unfortunately, another lesion was growing in the right side. The entire brain was angry. Again, it was the logical time now to ask for ‘comfort treatment’. Who would ever want another brain surgery on the other

side for a terminal multiple brain cancers? He already exceeded the statistics with this brain cancer type “Glioblastoma Multiforme” and others called it ‘Gliosarcoma”. It was him that never lost hope and said yes to surgery. He felt his time was not yet at the door. Even for another day, week or month. “Any time with my wife and kids is priceless. It is well worth it” He was very much worried about his wife and kids. Their well being meant the world for him; “I am worried about my wife and children. She is going to be by herself, I will not be by her helping her to raise them and to care for them and be by their side. I will not be by our children as my parents were” the hidden tearful eyes and the soft voice were talking. Another surgery was done but on the right side. The tumor piece on the right would have killed him in days if he did not go for surgery.

THERE IS NO GOOD TIME TO DEPART NO MATTER HOW READY YOU ARE AND HOW LONG YOU ARE PREPARING YOUR SOUL

I am worried about my wife and kids. The man of the house will go what will happen to the house and household. My thoughts can not stop worrying. He searched within his mind and searched. He assessed the situation and looked at his family. “I am not ready, I will go for everything to grant me life with my children and wife” The chemotherapy changed to stronger one. This chemotherapy was administered intravenously. It was stronger medication and would make him tired for a week. Yet, he recognized he would do anything to live one day longer with his family. He entertained other opinions. He flew to two other States and received different treatments. He tried alternative medicine. His records were sent to other major medical centers. The results were the same. Nothing else was to be done. Out of compassionate care, focused high dose radiation was administered with the stronger chemotherapy. The tumor continued to grow regardless. The brain tumors were all over the brain in different sites. The tears were running when the MRI films and the news were delivered to both. The husband and wife were inseparable in any step of the care. The faith however, never departed the house. Many healing ministries were coming and going to the house. “We believe in miracles. We loved the miracle prayer. We did not stop waiting for a miracle” the patient and his wife said these words with deep faith.

THE FINAL JOURNEY

A phone call from the wife: “Last week we were in the “Cubs” national league Baseball game. Today he lost the sight from the left eye and the hearing from the

left ear. He needs help to walk around” the wife said with tearful eyes while trying to grasp her breath; “I think his time is approaching. I am trying to still encourage him to go out. I do not want him to lose hope and give up. He was doing great.” Ghaly answered “It is the time to start the comfort treatment. The cancer is growing regardless of what science is doing. He fought the good fight. We need to comfort him now” the wife kindly ended the conversation “I know”. The hospice was called. A question was asked by the wife, children and his parents; “What to expect?” Ghaly said “The body will not suffer because his mind will decline. He will gradually drift away with the weary flesh. You who have their mind will suffer. Be strong and know that we have been blessed to prepare for such time for almost two years” He lived for two years despite the fact that this was an aggressive inoperable cancer. “When you see him talking more and more about his son Mitch and seeing his face, know that the time is near” Ghaly said while visiting his house. He needed assistance in every step. The smile and love were in his eyes. The look of sainthood was in his face. He looked weak by the flesh but strong by the faith. He had never said one negative word or complaints throughout the entire illness journey even to the last minute. “Here is the statue of Christ and the statue of the Virgin Mother of God Saint Mary in the house. Both will come to take his soul soon. Perhaps, it will take four weeks or less. His right eye will give out so his entire body” The tumor was eroding the brain in its depth. The tumor made him hungry and thirsty all the time. He gained tremendous weight. The tumor was also in that area called “Hypothalamus”.

PARENT CAME TO COMFORT THEIR SON

His parents came from Florida after the first surgery, the second surgery and finally at the end to bury their beloved son. The parent had many things to say about him. There are no words to describe his personality. They will give disservice. Here are some of the words from the blessed parents; “Always with a smile, cheerful, giving, joyful, obedient, tolerant, compassionate, hardworking, faithful, generous, He will always going for the extra-mile service to others. He has a glamorous face and never have we heard a single complaint. When the neighbors were asked, it turn out that he had built their homes. He had build forty homes and remodeled many more. He became like a family for all that he had touched. He had served mankind and the country relentlessly. He had done great service for many people. He was indeed a Saint for us and not a patient.

THE COMMUNITY WAS PULLED TOGETHER FOR THE FINAL MOMENTS

The parents came to spend the final weeks with their son. They lived in Florida for thirty five years. They were of helping hands to the family. The neighbors were giving without asking. Anything they see the family in need, they would bring it over. The daily prayer service was going non stop for two years for him. Twice a week, a prayer service was conducted with the family and their friends. The family faith continued to grow more in depth by the illness journey. "I saw abundance of food in the house, many toys for the kids and many other items. It was a testimony of "Love bring abundance of prosperity even without asking" Ghaly said to the community. The News media was interested to write a story in the local News Paper in testimony to the faith and love that was brought by the brain illness. The brain illness took two lives, the dad and son and spared the wife.

Many of the neighbors and friends were coming to the daily prayers, up to a hundred people. They were all in one voice and support to what the family was going through. The silent Good Samaritan was many. A friend will come silently and get the dirty cloths from the house, clean them, and bring them back unnoticeably. Another person came quietly and left some home-made meals. A group of children came to the house and planted beautiful colored fall flowers and mounted hand written signs of support, love and friendship. It looked as if the entire community became the church of God. It was only one description to these actions which was the favorite word of JB and his wife is 'love'. The parents were able to teach each person the meaning of love and how to love. The Journal Reporter spent the final moments with him, family and the entire community. The story made the Headline News. It became not a story that was shared with the family and local community but a story for everyone to read. He left a legacy behind for generations to come.

THE LAST SUPPER

It was very difficult to see him going through the terminal features of the brain illness. He had to have two to three assistant to hold him. He could not walk steady. It was difficult for him to shave. For the first time, he neglected to shave his beard. He looked different especially with increasing of the body weight and swelling. Despite these difficulties, the family took him to his favorite restaurants. It got harder and harder. It brought smile in his face but it was too dangerous to continue. We all met for a dinner together in a restaurant close to his home.

Everyone was there. It was a wonderful but emotional time. The faith and trust in God was holding us together. To the last minute, he continued to express his gratitude to everyone. He verbalized how much he loved us. The kids were coming and going. They were worried but they were joyful that they were with their dad over a dinner table. They went briefly to the entertainment audiovisual center for children but they soon came back to eat with their dad. Next day, he had a major seizure and had to be taken to the hospital. God made him so in peace to the last minute his brain was functioning with consciousness. The faith however, never left them. Prayers were heard regularly. Many healing ministries delivering at home the healing prayers were the usual. "We believe in miracles. We loved the miracle prayer. We did not stop waiting for a miracle" the patient and his wife repeating the same words with blind faith. It was real emotional.



IN HIS LAST DAYS, HIS FACE WAS SURROUNDED WITH AURA AMONG HIS FAMILY AT HOME.



THE LAST SUPPER WITH THE PATIENT AND HIS FAMILY PRIOR TO THE SEIZURE.

THE LAST OFFICE AND HOME VISIT

The kids are struggling to accept the fact that dad is leaving the world. The mother does not know what to do. The kids had seen some consultants at school. But when they came home and had seen their dad in a difficult shape, their faces were full of answered questions and expectations. The mother requested Ghaly, their dad's neurosurgeon to talk with the kids. Perhaps, the kids with their parents can visit with Ghaly in his office. The kids had shown special attachment to Dr. Ghaly for his care to their dad over two years. Wife liked the idea and thought it will be helpful; "He likes to visit Ghaly clinic all the time". To the last minute, the patient could not make it. His condition deteriorated rapidly. The kids will come with their cousins to address their questions. Ghaly will pay the last visit to JB. He started to be short of breath and bedridden. He could not control urination. Other measures were used including diapers and Foley bladder catheter. He then could not walk and became bedridden. He needed assistance in bed. The seizures were awful. The hospice nurse brought anti-seizure medication

to take. Comfort drugs were handy. These measures initially were met with reluctance from the family but as the condition got terminal and hopeless, they became open to use them. The entire family including the patient was involved in daily prayer services. The home became a little church. The home prayers were joined by the heavenly prayers and were presented like innocent before the Almighty. He was the Healer.



WHAT TO EXPECT

The mind has wondered from where you start to address the departure mystery that occupied the human mind for thousands of years. In regard to the youngest sons aged 6 and 8 years old, the brain has not developed the full concept of death yet. In regard to the three daughters aged 15, 16 and 21 years old, the brain has developed good sense of what death is all about. Nonetheless, children of all ages need support and reassurance that fatherhood and other members of the family are going to be around and the foundation is not changed. “The father is going to a better place. God has called for him. Nothing else will change. All of us are continuing to be with you; the mother, cousins, aunts, grand parents,—etc” Ghaly said to the kids while touring the office. Hard days are coming for this family. God be with them. They departed the office with peaceful thoughts at least for now.

In the last few days of terminal brain cancer, what to expect is a common question and is usually raised by the patient and the family. The awakening will gradually be lost; he will become sleepier, will not talk much and eyes shut down. He will not respond unless he gets stimulated. Initially, he will be patchy in his awareness until he becomes unaware of the surroundings. The look in his eyes and face will be radically different and the term “he is not himself anymore” will be rightly said. The sharpness of the mind becomes unclear. He will not remember things and the brain loses its perception. He will not consciously suffer because his mind is cloudy and loses its cognition. He will have difficulty talking or selecting the words. It may be difficult to find out what he wants. The speech becomes slurred. He will not be able to think or focus in any task. He may recognize that he has a headache or he will put his arms around his head. Medications to comfort the pain and headache can be ordered. Medications can be given to reduce the increase in the brain pressure such as mannitol, glycerin and urea. As the pressure inside the brain increases, the decline in all the brain functions worsens. Ultimately, death will occur from brain herniation and strangulation. The brain will be so swollen that it will die away. The mind gets strangulated. His vision becomes affected and ultimately will not be able to see or read. Eye patch and protection may be needed. Safety measures to prevent falls should be implemented. The helping hand may wish to talk to him and read things slow and clear. He will not be able to write or hold things. He will lose his balance and will not be able to walk or sit. Assisted device (s), such as a cane, walker, reclining chair and transfer board, may help out. He may not be able to turn and protect his skin from soreness or ulceration. The helping hand can change positions frequently, turn him and pad the skin. He will not be able to care for himself. He will not be able to clean himself, brush his teeth or feed himself. He will need assistance in every little thing of the human basic needs. Hospital bed, bedside commode, shower head and other hospital devices may make personal care easier at home. For many, it is much more comfortable to make the home a small hospital while caring for the final days of the loved one. He will spend the last days with his family inside his home. The terminal brain also is much more familiar with the home structure and friends more than those in the hospital setting. The suffering and hardship on the family members will heighten especially they are, and not the patient, are aware of what is going on. Many Good Samaritan hands needed. In addition to hospice and visiting home nurses, others may include; family members, neighbors, friends, social and psychological services and spiritual ministries and chaplains. These services will be needed more than ever. These may include; tremors, and involuntary movements of the arms and legs will be seen.

He may have seizures and stiffness. Anti-seizure medications can be given. Calming medication can be administered for agitation and combativeness. Also, drugs are available to helping patient sleeping. The appetite gradually decreased and he will not want to eat or drink. Liquids and food can be administered through a Naso-Gastric tube to prevent the pain of sense of thirst and hunger. The breathing gets shallower and the lungs collapse. The breathing gets harder and he will not be able to get ride of the normal secretion. Pulmonary toilet and supplemental oxygen can be given to prevent the sense of suffocation. The suction device can be used to clear the secretion from the mouth and to avoid the harshness of respiratory suffocation. He will not be able to control urination and gets constipated. A Foley bladder catheter can be inserted to keep the urine in sterile bag. Laxatives can also be administered. The temperature rises up and antipyretic drugs may be given. It will be no more immunity or self defense. Bacteria and other organisms will find the body attractive place to live and multiply. Antibiotics can be administered. At this point, he will be comatose and unresponsive. Each organ will start to fail until he takes the last breath where the spirit will leave the body in peace. Tissue donation is possible for terminal patient dying at home and not organ donation. In other words, organs such as heart, liver and kidney can not be harvested but tissue such as heart valve, bone and cornea can be harvested and transplanted to a living human being after passing the compatibility tests.

PATIENT EMPOWERED CARE DURING HOSPICE CARE

No one else can provide excellent care with compassion than the closest family members. They are the center of the care. They are available 24hours and 7 days/week. The medical team will educate the family members and elevate to be the primary care giver for the loved one. The chapter was written in Volume I under "Patient Empowered Care". Even to the last days of care, patient empowered care is still superior. There is a gratification to family care givers to be of help to the loved ones. It is also giving them a transition and good perspective of what to expect as the time come closer for departure. They are patient advocate and they will never consider their loved one as a number. They believe in quality care. It is my experience that family care givers are tireless, non-complainers, persistent and goal oriented. They give the impression that it is their privilege to care for the patient and they will do everything in their hand to get him through the illness. The family members know their loved one well. They usually can give an accurate impression regarding the patient needs. Many things can be understood from the patient routine, facial impression, and behavior. I was always fascinated with

the diligent care that each family member is eager to administer. The family member is writing down what he or she is giving and what is the output. The medical diary will be helpful. Questions will be asked by the care giver and answers will be given from the medical team as well as from the other resources such as library books and internet service. On the other hand, in our modern society, the daily routine does not stop by illness. The person has to go out of his way to help out. The society regimen may become punitive to accommodate disability. It almost looks like in the rapid pace society; man is running after the clock and not the clock after the man. It is barely manageable to live in such a society even when the person is healthy and active. What about if the man of the house is sick? This is because the mainstay of our society is production. In such a society, it is important to thank the helping hands. Because it really means a great deal of sacrifice. Therefore, the load in caring for patients and prolonging their lives is tremendous and need physical, financial and mental contributions.

As JB terminal cancer was coming to an end, it was eye opening for me. I was preoccupied with his legacy of hardworking citizen, and his extraordinary love and compassion. The hospice team believed that hydration and feeding were not necessary. Comfort medication sufficed. I believed that starvation and thirst were painful and feeding via a nasogastric tube and hydration with liquids were part of the comfort treatment. However, they will prolong the inevitable. We gave the options to the family. Ghaly wrote a protocol for the comfort treatment of terminal cancer patient who is dying at home (see below). The family agreed to pursue the protocol. The dedicated wife carried on the protocol literally. She felt that what she was doing was alleviating his pain and suffering. She also was excited to see him at least once in a while answer back saying "I love you". "Good bye my son" he answered his child while opening the door and going to school. "Thank you" he answered his daughter while asking him for anything he needs. Although, in his last days, he was bedridden with total assistance to move him, it was a joy for the wife and kids to be able to say "Hi", "Bye" and "Love you". This feeling did not change even with the 24hours and 7 days/week dedicated care by the family and medical team. Health system will not support the "to the end" care without family sacrifice. Unless dedicated family care givers 24/7 are available at the bedside, they loved one will not make it. Health care has limited resources. The expenditure "to the end care" can be tremendous. Every day the terminal patient lives is a gift of life but it is unfortunately to others "money lost" For these reasons, it is not uncommon that the terminal patient will be dehydrated and starved until death occurs. The protocol brought more days for the dedicated wife and parents were at the bedside caring for their loved one. The

kids were going and coming to school. The mother was trying to comfort them and make them slowly go back to their routine life. "Good bye my dad" the kids each would say as they leaving to school at 7am. "Hi dad" the kids were saying as they coming back from school. The oldest daughter would give a break to her mom so she could go outside for a walk. The protocol was a learning experience for the hospice staff.

JB was on a treatment plan include the following:

RESPIRATORY

- Suction at bedside
- Nasal trumpet at the bedside
- Nasal cannula Oxygen 2L PRN

GASTROENTEROLOGY

- Laxative (Supp. 1bid PRN)
- NG tube flexible feeding tube: (Before feeding please check tube secured at the nose >45cm (for adult) and not coiled at the mouth and no regurgitation or vomiting)
- Water flush 200cc q 6hr
- Highly nutritious concentrate 70cc/hr from 10p to 6am
- HOB elevated to 30 degree while feeding
- Ant nauseating drug

HYDRATION

- Saline lock IV and every other day IV care
- Pick line
- Peripheral IV with balanced solution over 8hr daily if not tolerate mouth feeding

UROLOGY

- Bladder Catheter to Gravity
- Clean around Meatus

BRAIN SWELLING/HEADACHE

- Brain diuretic medication iv
- Brain swelling medication of steroid origin
- Other medication by mouth to decrease brain swelling (if available)
- Stomach protection drug against stomach ulcer

SEIZURE MEDICATION

- Ant seizure Medication (one or two to prevent seizures)

PAIN AND AGITATION

- Anxiolytic medication sublingual
- Narcotic medication for pain

SKIN and EYE CARE

- Patient turn q2hr
- OK for reclining chair
- Check skin status daily
- Chest PT as needed
- Artificial Eye tears q 8hrs

DEEP VENOUS THROMBOSIS

- Tight leg stocking
- Pneumatic compression
- Anti-thrombotic injection

PHYSIOTHERAPY

- Physical Therapy
- Occupational Therapy

SOCIAL AND SPIRITUAL SUPPORT

- Spiritual minister consult (Chaplin)
- Social consult
- Psychologist (if Applicable)
- Psychiatrist (if applicable)

KEEP A DIARY FOR MEDICATION AND INTAKE AND OUTPUT OF FLUIDS

Hand written at the bedside with important phone numbers of the medical team

TISSUE DONATION

Call Organ Donors to discuss the donation of tissue and make arrangement once death occurs.

Not only, has JB continued to make a difference while he was dying to help develop such a protocol but also brought another idea to our mind. “What would the kind heart of JB do” Ghaly mind was thinking. “Can some parts of his body be harvested to bring life to other patients?” Ghaly asked the Gift of Hope organization. Sure enough, tissue donation was an option. It was a strange idea and had not been done before in the area. Not many people were aware of it. The Organ Bank was contacted and arrangement made that once he was expired, a car will be taking him to a nearby hospital and then returning his body back to the funeral home. Another idea came to mind of developing a “Mobile Hospital and ICU” to be handy and provide more service to the needy. Because of JB, many ideas have started to spread JB love to others. Another idea came to Ghaly mind to establish an immobile hospital and ICU to serve patients in crises. A letter was then sent to that effect. Even in his last days, JB was helping many others. Love is unlimited, my friends.

The grieving days are unimaginable to the loved ones. They start far before the departure time and extend thereafter. The scars will be carved in the heart. The loss will not be forgotten or replaced but it can be eased for a little while. The faith and closeness to God will be the best healing medication. Each person needs to support the other. The kind touching hands of the family members and the outreaching arms from the community are in desperate needs to minimize the pain and the impact of losing the loved one. It is OK to cry. It is also wise to speak about what is in your heart. It is Ok to repeat these words of wisdom; “He is going to a better place. He suffered enough. He is going to rest and be comforted. God is calling for him.” It is also wise to flash back with the good memories of him; go over what spectacular things he had done, what achievements he had acquired and what sacrifices and hardships he had endured. It is wise not to be lonely or keeping things to yourself. He has to leave; his calling is at the door. The loved ones need to let him go and not to be in the way. It is essential for the

kids to continue to feel loved and supported. The closer family members are seen around. The foundation of the family structure is unchanged. It is also important to address the health of the family members; making sure their needs are being cared for. These may include personal care, nutrition and change in environment. The brain thoughts need to also include remarks of the kids to their father as if he is still on earth. For example, they will continue to adhere to the Godly deeds and being outstanding citizens in the world that their dad and mom have brought them. They will continue to be the best example possible for whatever they do. Their dad physical presence is gone, but he is present by the spirit. He is watching from up high and helping them. In fact, he is praying for them to the Lord and will become the family advocate to the Lord.

LET US PREPARE FOR THE COMING OF THE HEAVENLY HOSTS TO OUR HOME AND COMMUNITY

The wife, kids and close relatives and friends took off work. They were by his side. They were administering minute to-minute medical care. The visiting nursing was coming for few hours almost every other day. The hospice was supplying the medication and the necessary medical equipment. He was lying in the hospital bed and alternating to a reclining chair. The kind stories of him and Mitch were being told. The atmosphere was so emotional. The memories were mentioned with sense of love and proud ness. The kids came and hugged their dad and cried. Their dad was in deep sleep. He was wrapped with spiritual cloths and religious chains preparing for the groom to meet the bride. Miraculously, he will whisper the name of the crying child and put his hand with the child hand. It brought some comfort. The family members were alternating position close to him. The heavenly Father has the answers of many questions that are asked by the human brain in such a difficult condition. The family members turned their heads and eyes to the Lord. The Lord sent His Holy Spirit to comfort each and all of them one by one. He is our Father and Father of fathers. He is the kindest, sweetest and merciful Dad that mankind ever known. The children were praying with tears to Him. The candles are burning and the religious statues were visible to every visitor. The Mother of Jesus came to be present with the patient and family. Her statue was glamorous. "Hail to Mary the Queen: the unaged vine: that no farmer toiled: In her is found the cluster of life." (Coptic Christian Hymn of the Virgin). The holy pictures and statues were talking to each of them. What a sacred place. The small church was being ready for the heavenly hosts to come and pick up JB spirit for the final rest. Jesus Christ is the true eternal Father and the most compassionate God. He was incarnated, nailed on the cross and died for

us. Listen men and women, let us turn our brains and minds to Him and He will come comfort JB and the entire family. The kids were praying for Jesus the Lord to prepare the heavenly mansion for their dad. He will be coming to pick their weary dad from his bed and take him up high to the eternal joy. The children and family were praying to the loving Father to reveal His coming to them and His sooner mercy. Whenever the children were crying, their tears were directed to God, their true Father and to our mother, Saint Mary. What a party! The holy city of the Great King will be adding a new person named JB. He fought the great fight and will be glorified with the true glory. The mother of mankind; hail to you the blessed mother, is in the house. Everyone is praying to be worthy to see the spiritual vision of God salvation. The priest came and handed the communion to the patient. If you looked around, it was easy to see the home of JB was the temple and the community was the remainder of the church. The earthly community was joining the heavenly one to prepare and celebrate the new addition to the true kingdom of God. The house became the entire house and community

IT WAS WORTH EVERY MINUTE

Some will disagree in regard to the aggressive approach in handling JB case. If no surgery or small surgery was done back in January of 2005, he would have lived for few weeks and passed away peacefully. With raising healthcare costs, the financial challenges that faced this family were tremendous. After all, we would prolong the terminal brain illness and increase the suffering. On the other hand, every minute of human life is priceless, and God is the ultimate authority to take a life. While on earth, the medical team is called to save life and not to prematurely terminate life. Ghaly discussed the pros and cons of each approach with the family. He also asked them retrospectively; "If you have to do it again what would you have done?" The answer was the same for every step of the way. Every minute he lived to be with his children and wife was worth millions and millions. Each minute had brought him closer and closer. For Ghaly, it was a long journey to care for JB, but it was well worth it. It is my experience that no one wants to see the loved one go. By letting each patient live as long as possible should not be viewed as; "prolonging the inevitable." "So want him to live. She will not let him go" the hospice nurse said about JB wife. With each minute of life, there was always hope. The book on earth is for ever closed by death.

THE LAST BREATH

The intuition came to him and his family; the time for his life to be completed is now. When the time came and give-up the spirit, the loving family was at his bedside. His spirit departed with peace and comfort. The place was holy and sacred. He took his last breath and his entire body became flaccid. The heart beating stopped. The eyes closed. The living color of the flesh went away. The skin became pale, cold and bloodless. The lips darkened. The nails and spine stiffened. There is indeed a great deal of insight into the last breath. By the last breath, the flesh immediately dies and the spirit is immediately released and freed. During the last breath, the mouth may open and the air is expelled. Perhaps, this is indicative of expelling the spirit out of the body, the physical prison. It is the final sign that is meant for each expiring mankind regardless of his or her rank. Jacob, the prophet and Jesus the Lord in the flesh experienced the same last breath; “And when Jacob had finished commanding his sons, he drew his feet up into the bed and breathed his last,-”(Genesis 49: 33) and “Jesus cried out with loud voice, and breathed His last.” (Mark 15: 37) and “And when Jesus had cried out with a loud voice, He said, ‘Father, into Your hands I commit My spirit.’ Having said this, He breathed His last.” (Luke 23:46). It is the time that the heavenly visitors come down and take the human spirit out of the body. It is the sacred time where heavenly peace comes from above and hover over the face of the house and household. It is the time where the human spiritual eyes open and start to see and hear what belongs to the spiritual world and what is beyond the physical world and its physical boundaries. During the last breath, the facial features change and leave a lasting impression to everyone standing by. Hopefully, it will be an angelic with peaceful aura to all of us as it was for JB.

ROAMING OF THE SPIRIT

Everyone close to JB felt his presence after death. The atmosphere changed and the perception has changed. It is no longer JB, the disabled unconscious fellow lying in bed helplessly but rather the free energetic soul that he is “all over the place”. He is making sure that the earthly people know that he is well and alive and close by. The perception and feeling of each person can not be expressed to know why by the departure of his soul things change. It is perhaps because the changes are spiritual and invisible. He is sending us many signals” wife and mother said. “He always told me that he will be close, the light will turn on and off when we call him” said the wife as she described the light in the funeral home went off all of sudden while making the arrangement for his funeral. The roam-

ing of the spirit was one of the biggest comforting measures to all his family. It made everyone believe that he is finally resting and alive. He was not dead but alive with God. The kids felt their dad's spirit. "Is my dad walking and going up and down the stairs now in heaven, mom" said the youngest child while he was unhappy to see his dad by the flesh lying helplessly in bed for almost three weeks unable to move. His funeral was special, people came from every where. The close family did not much about his love to many and his outreach service to many more. "I did not know many things that were mentioned in his memory during the service" said his mother. "The minute he took his last breath, a smile came to his face immediately" said the wife. These inexpressible works after death remind us with the first risen, the Son of Man Jesus when He send many signals to proof His resurrection and being alive and not dead. The family members felt many blessings are coming to their life. They were very much consoled and comforted with all these miracles. The death of JB transferred to a joy with his liberation from the pain and suffering of the flesh and from death to life and from sadness to eternal happiness. The roaming of the JB spirit has wiped the tears from the eyes and took the sense of grieves and loneliness in the heart to faith, joy and hope. By knowing their dad is alive and rested, the kids were able in a short time to go back to the daily routine and continue their mission until their time of departure to meet him face to face once again in the eternal kingdom. "I know he is around and hearing us. I see many signals in every step of the way" the wife said as she is holding the household together and preparing to go back to work and continue her mission to raise the kids

For now, the wife and kids are living with the memories. The wife has been taken notes for what they both discussed. In his last three months, he apparently talked much about his personal insight in regard to his wife and the future of his kids. The words were being repeatedly heard in their ears at different scenarios. These words were being prepared in a book to be read by all the children and grand children. The unspoken words were being heard when questions arose. "What will his dad do after his son have don so and so?" the mother is asking while looking at JB photo. She immediately heard the answer within her mind. Her belief continued strongly that JB is with her and her family and never lift them. She felt comforted. "If there was no plane for miracle to take the brain tumor out, why, then my son, JB was going to the healing prayers every Tuesday?" JB dad asked while looking at the picture of the heavenly Father. Immediately an answer came and comforted the dad; "Shouldn't we care about his heavenly comfort more than his earthly comfort!" Many more examples.

Through the memory book, the dad and mom will be alive to all the their children and grand children.

DE-GRIEVING

The community service did not stop after death and burial support. The supportive and compassionate care continued to pour into the grieving family. Their needs were being addressed by the ministries and parish. Some of them were meant for de-grieving. It consists of personnel that had prior personal experience with lost ones. They stretch their arms to help anywhere they can. They are good listeners and understand what the grieving family is going through.

FOURTY NINTH BIRTHDAY AND TWENTY SEVENTH ANNIVERSARY: CONCLUDING WORDS

JB spirit spoke and said many words. It is my birthday on October 27, 1957. My Lord wished for me to celebrate the forty nine birthdays with Him and my son Mitch. While I am there, I will be also celebrating my birthday with you. My family, I wish for you to prepare my birthday cake and place the 49 candles along with a large one. I will be coming briefly to blow the spiritual air over the 49 candles. My spirit is hovering over the house. I will keep the large candle burning. It is a memory for my crowning after passing through the 49 years on earth. It is the candle of the “well done faithful servant” as the words of my Lord said; “Well done, good and faithful servant; you were faithful over a few things. I will make you ruler over many things. Enter into the joy of your Lord.” (Matthew 25: 21). I am in joy. It is much better for me to be here in the paradise. Do not cry for me. It is not a permanent departure. It is only for a little while. I will keep a place for all of you, my family. Do not be tearful!

In regard to the anniversary, I will be coming from up high and be with you. My loyal wife I will never forget you. You are not alone, my dearest wife. We have been together for 33 years and we will be together for ever more, in eternity. Until then, thank you for caring about our kids and family. Thank you for caring when I needed you most in my final brain illness journey. Sorry, if I had been of burden. Moreover, I am also sorry because I departed early before completing the mission with the kids. I was called to heaven. It was my time to leave the world. The mission is in your shoulder. Your cross is heavy, but Mitch and I will be there to comfort you.

I have considered the suffering during my illness journey on earth a blessing to earn eternal life. My sick brain was repeating Saint Paul words; “For I consider

that sufferings of this present time are not worthy to be compared with the glory which shall be revealed in us. For the earnest expectation of the creation eagerly waits for the revealing of the sons of God” (Romans 8: 18-19). When my moment of departure came, I praised my Lord and said; “I have fought the good fight, I have finished the race, I have kept the faith. Finally, there is laid up for me the crown of righteousness, which the Lord, the righteous Judge, will be giving to me on that day,-”(2Timothy 4: 6-8). I finished the race over my brain cancer. I passed the struggle over my entire earthly journey.

Rejoice the community of JB because another angel was chosen to be with God. The hosts of heaven are preparing for the celebration on the moment of departure. The community was worshipping the Lord with praises of His holy name. Let us all earth praise our Lord, glorify Him and exalt Him above all as God and lover of mankind; have mercy on us according to Your great mercy” (The Coptic Christian prayers of the Pentecost Feast Doxology).

JB looked to the people and said “You all in my heart. Thank you. I pray for all of you.”

Good bye my friend for now. It will not be for long before our time will come. We will be all celebrating the fruits of the vine with our Savior and loving God Jesus Christ; “for I say to you, I will not drink of the fruit of the vine until the kingdom of God comes.” (Luke 22: 18).