

A practical guide for stroke victims and their loved ones.

There is Life After a Stroke

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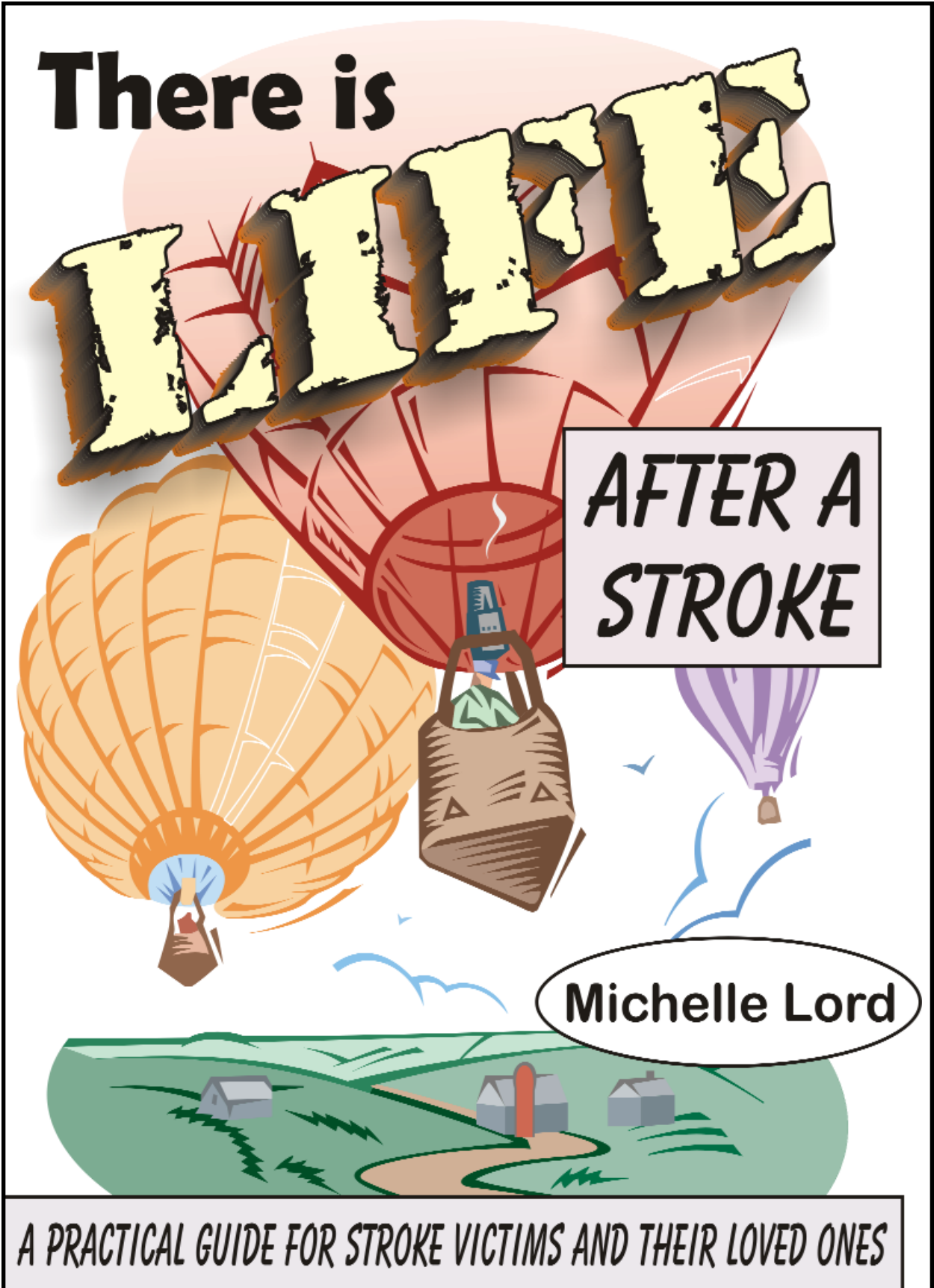
There is

HELP

**AFTER A
STROKE**

Michelle Lord

A PRACTICAL GUIDE FOR STROKE VICTIMS AND THEIR LOVED ONES



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Table of Contents

Letter From Michelle Lord1

Chapter 1 The Fateful Day2

Chapter 2 Rehab Experience8

Chapter 3 Taking Care of Yourself13

Chapter 4 Taking Care of the Stroke Victim.....18

Chapter 5 Sex After a Stroke22

Chapter 6 Special Equipment and Clothing24

Chapter 7 Choosing the Right Transportation.....27

Chapter 8 Financial Hardship Following the Stroke29

Chapter 9 Children and the Effect of Stroke on Them.....34

Chapter 10 Your Life Will Change – Preparing Others37

Chapter 11 Traveling With a Stroke Victim40

Chapter 12 Depression and Other Issues After a Stroke43

Chapter 13 Working Again and Disability.....49

Chapter 14 Our Life After the Stroke53

Chapter 15 Statistics and Stroke Prevention58

Chapter 16 Resources for Families of Stroke Victims66

*I would like to thank all who have been an inspiration
and helped me to make this book a reality.*

*I also want to thank Gene, my loving husband,
who has put up with me all these year, and thank you to God,
who gave me the talent and the words and the ability to put them to paper.*

Note from the author:

Hello,

My name is Michelle Lord and my husband Gene suffered a massive stroke on September 11, 1996. In a split second on that fateful morning our lives changed forever. This has been a very tough journey for us, but it has also been a learning experience. I wished back then that someone had explained what to expect, what not to expect, and had given me a little insight on how different our lives would become. That is why I am writing this book. This book is our experiences in the last seven years. I get a bit personal at times, but I feel these are things you should know. This is not an impossible journey, but it will be a hard one, and the more you know up front the easier the journey will be for you, your loved one affected by the stroke, and your family. I am far from a stroke expert, but wanted to share what I have learned along the way and am still learning every day. Please feel free to contact me with any questions or concerns you have on your new journey. Sometimes all we need is a person to listen and then we can make the choices needed to move on with our lives.

Sincerely,

Michelle Lord

msnotes@hotmail.com



The Fateful Day

September 11, 1996 is a day my family will never forget – a day that completely changed our world. It started out as a typical morning in September - everyone was rushing around, getting ready for the day. I stood in the bathroom trying to do something with my hair, while my husband Gene started his normal ritual of spending some time on the toilet. Something seemed different though... his speech wasn't right, he was talking gibberish. I could not understand what he was saying, but I was in a hurry so did not think a lot about it. When he kept trying to talk to me I decided to walk over and ask him what was wrong. When I walked over to him, I saw that the left side of his face was drooping and he couldn't move his left arm. I did not know what to do, but I knew something was wrong. I told him to stay still, and yelled for my daughter to go next door and get her grandfather. At the time Gene's parents were living in a motor home next to our mobile home. We lived out in the country on 11 acres in a small town called Cleburne, which is about 30 miles from Fort Worth, Texas. Gene kept trying to get up, but when I turned back around to tend to Gene, he had fallen off the toilet and was face first in the laundry basket. I couldn't move him or do anything for him; I felt so helpless. Then my father and mother-in-law came rushing in and yelled, "Oh no, he's had a stroke." I wanted to put Gene in our car and get him to the hospital, but we just weren't strong enough. Gene is a large man, and always has been; and the three of us just could not move him. There was no choice but to call 911 and wait for the paramedics. We lived far enough out in the country that I knew it was going to take quite a while for the EMS to get there. We were in an area where we had a volunteer fire department and so you had to wait for the people on call to respond. In the meantime, we put a blanket on Gene and tried to keep him comfortable. Gene wanted to get up but just could not do it.

It seemed like an eternity before help arrived. Sirens were blaring outside as the paramedics rushed into our house. One look at Gene and they knew they had to work fast. The problem was, he was a very large man and no one could lift him. They had to improvise by rolling him onto a blanket and then dragging him through our trailer. Once

he was finally loaded into the ambulance, I got in my car and followed them to the hospital. The hospital was only about 10 minutes from our house. On the way, I started praying and thinking of every pastor I could call and every prayer warrior I knew. I knew that this was a dire situation and we needed all the help we could get. God must have been watching over the situation because when we arrived at the hospital we were greeted by a nurse that knew Gene from many years ago. She had heard his name over the radio and started making the arrangements to send him to Fort Worth. She told us that the Cleburne hospital did not have a CAT scan big enough for Gene, so they were going to have to transfer him. I was so glad to hear this, because the Cleburne hospital was small and I knew he needed to be in a bigger more equipped hospital. We were only at the Cleburne hospital long enough for the transfer into a different ambulance and then we were gone.

The trip to Fort Worth, normally a 45-minute drive, seemed to take forever. I couldn't ride in the ambulance, so once again I followed it in my car. I did not know what to think. Gene was only 36 years old and now he was on the brink of death. I was in a daze trying to figure out what to do, who to call, and what was going to happen next. I did not realize at the time that our lives would never be the same and that we were about to go through one of the hardest few months of our lives.

We arrived at Harris Hospital and the emergency room doctors started working on Gene. They told me to wait in the waiting area and they would get me once he was stabilized, It seemed like forever. After 20 minutes, one doctor finally came and talked to me. He told me that Gene had an extensive bleeder in the base of his brain. It was a right ganglion bleed. They could not operate in that area, so it had to stop bleeding on its own or Gene would be dead within 24 hours. I was 35 at the time with three teenagers - I was not ready to be a widow. I called everyone I knew and told them to start praying. I called people I had not talked to in months and told them to pray every healing prayer they knew, because this was in God's hands now. I had several people come to the emergency room and try to comfort my family and me, but at that time it was just a waiting game. The next morning the bleeding had stopped. He had a 4.5 cm tear in the

vein and if it had bled just 0.5 cm more all his major organ systems would have shut down and he would have died.

They finally let me see him in the neurological intensive care unit. I could only see him about four times per day for only a short period of time. Gene to this day does not remember the first seven days after the stroke. He basically would lie in bed and moan. He also complained of severe neck and shoulder pain. They were giving him so much painkiller and other medicines that he was not able to communicate at all. The entire left side at that time was dead, but he was able to swallow and talk, which is a wonderful thing, because a lot of stroke victims lose that ability and that causes a whole different set of problems. Finally after a week they put him in a private room and I was able to stay with him around the clock if I wanted to. The funny thing was that they had forgotten to me that they moved him and I was waiting for the specified time I could see him in the ICU. I went to the ICU and they told me that they had moved him something like two hours earlier to his own room. They had to help me find where he was.

Gene was to a point where he could not feed himself. I tried to be there for most of his mealtimes so that I could feed him. He had to have a bib because he drooled on the left side of his mouth. He could barely sit up in bed and kept falling to the one side. He could not walk, stand, sit-up, eat, *anything*. It was like he was a baby again having to learn how to do everything. His main neurologist just wanted to send him to a nursing home. He said Gene would never get well and we might as well face facts. I told him he was wrong and I wanted them to do a physical therapy evaluation. He reluctantly agreed and had physical therapy come and look at him. This wonderful man came and evaluated Gene. He felt there was hope. He knew Gene was only 36 and that he was too young to give up on. The problem was that Gene was a very large man (400 pounds) and it was going to take extra effort to get him up and moving again, but the physical therapist wanted the chance. He and his team finally persuaded the neurologist that there was a chance and asked him to let Gene enter rehab. The neurologist reluctantly agreed and gave them two weeks to show some improvement. We then started down the road to rehab.

Gene was then moved to the special rehabilitation center they had at the hospital. He would be there for two months. He had his own room and a special bed that was designed for a man of his size. The bed was designed to stand completely upright so that the patient could be stood up and helped out of bed. This bed, however, had not been designed very well and Gene could not see the buttons to control the bed. On a couple of occasions I had come in to find that Gene had accidentally stood the bed up to the point to where he was sliding off the end and could not get up. On one occasion they had to call security to help get him back into bed. They told us that the manufacturer was going to fix the problem. But, it definitely made for some interesting situations.

The long progress began of helping Gene relearn how to do all the things he had known to do since he was a child. The first major step was teaching him to sit up. We then moved to standing. They were so happy one day when I walked in because Gene had stood up for the first time since he got there. They then taught him how to walk again. Rehabilitation was grueling and slow. There were several other stroke victims in the unit when Gene was there. Gene got very lucky in one respect because he did not have the problem with swelling that some patients have. The affected side sometimes swells very extensively. You would see the other patients with special hose and slings on to help this problem. Gene was having problems with his urinary system trying to shut down. They were very worried at one point that his kidneys were trying to quit. We finally got over this scare. They were also giving Gene shots daily to keep his blood thin. He would have huge bruises all over his stomach from these shots. They also had to watch his blood pressure. His blood pressure would drop sometimes when he would stand up and they would have to lay him back down and not do rehab that day. He also had constant pain in the neck area on the side where the bleeder was. He had a miserable and painful two months of in house rehabilitation, but he persevered and made it through.

I was having to work full time while Gene was in the hospital and I so wanted to be with him during his rehab time, but Gene's parents were both retired and they were able to stay with him during the day. I would try to see Gene every morning before I went to work and then in the evenings I would come and eat dinner with him. I tried to be there

for his dinner so I could help feed him. Gene was close to where I worked, but of course we lived so far away from the hospital that I was making two trips a day back and forth from Cleburne to Fort Worth. I was driving around 200 miles a day and was surviving on about two to three hours of sleep. I kept this up for two months. My employer was trying to work with me, but they did not understand exactly what I was going through. I was working for a big accounting firm at the time and I was responsible for the typing, printing, and binding of annual reports for the companies that they did the books for. It was year end for several companies so I was trying to take care of Gene, plus get all of these reports done and out the door. I do not know how I ended up getting through this time other than by the grace of God. I know they say that God does not give you more than you can handle, but at times I did not know how I was going to handle anymore.

The first couple of weeks people came out from everywhere to help. People I had not talked to for months or years came to help, but then the farther we got from the stroke the less and less people came out to help. Nobody truly understands what you are going through unless they have been through it themselves. The other day I had a lady tell me that her husband was in the hospital for a couple of weeks and she just did not think she was going to make it through with working and tending to him, and I told her I did that for over two months and had to commute. She just looked at me and told me she did not know how I was able to do it. It seems like when you are in the middle of a situation like this you just go into autopilot and some force just keeps you moving, keeps you going, and helps you through, and then when it is all said and done you look back and wonder, "How in the world did I do that?" I know that is what I did.

The rehabilitation staff was wonderful. They worked and fought for Gene. They kept telling the doctors to let them continue with his treatment, even though the doctors were telling me, first, that he would never walk again, then that he would never be able to feed or take care of himself, and finally that he really just needed to go to a nursing home. I told them they were wrong every time they tried to tell me any of that. I told them he was coming home and he was going to walk out of the hospital. They just kind of chuckled and went on. They just thought I was crazy or something of the sort. Then on October 31, 1996 Gene proved them all wrong and walked out of the hospital eight weeks after

being admitted - much to the doctors' surprise. There was still a lot Gene could not do for himself; however, he was ready for the next stage of rehab. Gene now had two more months of outpatient rehab to go through and things were not going to get any easier.



Rehab Experience

No matter what type of stroke your loved one had had, there is probably going to be some type of rehabilitation involved after the initial incident. The amount of rehab will depend on the extent of damage done by the stroke. Gene had major physical deficits after his stroke, so his rehab ended up lasting four months total – two months in hospital and two months day rehab while I was at work. Your rehab experience will completely depend on the attitude of your loved one, you, and the rehab team.

Even though Gene's main neurologist thought that rehab was a waste of time, he still signed the paperwork so insurance would pay for the treatment. Every time we saw him he stated his concerns and reasons why rehab would be a waste of time and money, but everyone from the physical therapist to Gene and I told him he was wrong and would prove it to him. Gene was just too young at the age of 36 to be in a nursing home the rest of his life, but he had a major physical challenge ahead of him, one that many people would never have undertaken. Gene could not walk, sit up, feed himself, dress himself, anything. The only thing he could do was eat and speak, basically, and he needed help with the eating. He was like a 36-year-old baby, only he still had the intelligence of an adult stuck in a body that could not remember how to do anything. Gene was also an extremely large man, and the neurologist did have a point. The only hope we had was a physical therapist who saw that Gene had potential. He felt he was too young to give up on and thought he needed to be in rehab. This physical therapist was a fairly young man who came and diligently worked with Gene. He and his colleagues then went to bat for Gene and convinced the neurologist to give them two weeks to prove Gene could make progress. The neurologist thought it was a waste of time, but went ahead and agreed. This was the turning point for Gene.

Gene then entered the hospital's in house rehab center. This center would become Gene's home for the next two months. He had a private room with a special bed they had to order for him. Due to Gene's size a normal bed just could not handle him, so he

had a special inflatable mattress that would help reduce the risk of bed sores. He also could not really turn himself, and it was designed to help the staff move him as needed. Gene was one of the youngest people in the unit. Most of the stroke patients were elderly people, and some of them did end up going to a nursing home, because it was just too hard for their loved ones to take care of them.

Gene's rehab course then began. The physical therapy staff had to start working with him in the room, because Gene could not even sit up by himself, so they had to start from ground zero. They would come in and work with him and finally got him to sit up on his own. They then worked on him being able to stand up. They had all sorts of special equipment and the bed he had would stand straight up so they could work with Gene on standing. I remember the day I walked in one afternoon and they had Gene standing. It was a wonderful milestone. Everyone was so excited, because now that he could stand up he could learn how to walk again.

Once he was able to stand up they started taking him down to the gym/rehab area and started him on special exercises. He had several therapists who worked with him, and they were all so wonderful. They all cared about their patients and did everything they could to help them succeed. All of the staff in the rehab center were wonderful. The nurses were caring and always had smiles on their faces. It seemed very hard to me how they could all stay so positive in what was a very hard situation. You had people who had major life altering events in their lives and some of them would never leave a skilled nursing setting, and they knew this. These caring professionals had to watch daily as people would have to relearn the simplest of task that most of us take for granted. Not many of us will ever experience the event of waking up one morning and not being able to use part of our bodies again, or having to relearn how to walk or even how to swallow so we can eat. Then to work with this daily and keep a positive attitude is an unbelievable thing to me. I know it would be very hard for me to do what the rehab staff had to do on a daily basis.

The two months Gene spent in the hospital were extremely trying months. My having to juggle work, being with Gene, tending to the kids and home, etc. at times became

more than I thought I could handle. Part of me was glad that Gene's parents were retired and could be there to help during the day with rehab, but at times I felt very left out in not being able to be there. Thinking back I am not sure if I really could have handled watching him struggle to take his first steps or the frustration he was going through trying to relearn what he had been able to do since he was a child. I wished that I could have been there more to help, but it was probably best that I was not. Finally on October 31, 1996, Gene was able to come home. After extreme effort and determination on his part he was able to walk out of the hospital. He had told everyone from the beginning he was going to prove the doctors wrong and walk out of the hospital and he did. The rehab was not over, but this was an incredible event that many said would never happen and it did.

Gene now had two months of part-time rehab during the day. I would take him in the mornings before I went to work and then picked him up in the afternoons. They continued with the physical therapy and also worked on his mental skills, skills of daily living, counseling, etc. They had counselors in all areas to help him learn how to adjust to his new disability. He at this point still could not take care of himself as far as dressing, hygiene, cooking, etc. He was home, but still needed major care. They also tested his mental functions to see what he had kept and lost in this area. His short term memory was basically gone, but he astounded them with his ability to do math problems in his head. He had lost his peripheral vision in his left eye and had what they call left ignorance. That is where he basically ignores anything on that side. This is very common in stroke victims on the side that was affected by the stroke. They had him do a lot of different types of memory games and games that tested his reflexes. They felt that games like this would help stimulate the brain and help it to start working again. Current research has shown that older people who continue to do crossword puzzles, read books, have intellectual conversations are less likely to have dementia because they keep their brains stimulated. This was the reason for the rehab team to have the patients do a lot of board type games such as Trivia, because it made them think. The more they stimulated the brain the more it helped the brain compensate for the lost and damaged areas.

Gene was in day rehab for two more months before they finally decided that he was at a plateau and they could do no more. He still had a long way to go, but now time was what he needed, and they had done all they could do. It was a very emotional time for all concerned. The rehab team got to see him walk out of the hospital, the doctor who said he would never be anything but a vegetable also got to watch him walk out. He had to admit he thought he would never see him do it. Gene had made a lot of good friends during that time and it was hard to close the chapter in that part of his journey, but it was time to move on.

The staff at the Harris Hospital Downtown rehab center was just wonderful and went above and beyond the call of duty. Gene went up and saw them a couple of years after leaving and said, hello. It was an emotional time for all concerned. Rehab was a great experience for us. We were lucky and had a wonderful staff and helpful situation for Gene. I do not think Gene would have done as well as he did if it was not for them. You really need to look carefully at where you let your loved one have rehab. You also need to fight for rehab if the doctor is trying to tell you it will not do any good. You will probably also have to fight with insurance to pay for it. Certain insurance plans do not cover rehab and you may have to try to find other options to take care of it. Gene's hospital bill ended up being over \$100,000 and the majority of that was rehab costs. Luckily, I had a very good insurance plan that covered most of the costs. If I had not, Gene probably would have had only two weeks of rehab and then would have had to go into a nursing home, because he would not have been to the point where I could take care of him.

If you feel your loved one has a chance to improve with rehab – *then fight for it!* Do not let a grumpy doctor squash your loved one's hopes of rehab and a chance at rebuilding his or her life. If you do not get satisfaction with one doctor then get second and third opinions. The only way we ended up where we did was because one physical therapist thought there was hope and fought for us. Rehab can make the difference between recovery or a lifetime in a nursing home. Also, make sure the rehab center will include you in the recovery process. Tell them up front if you want to be in the rehab sessions, or to be able to spend the night with your loved one, etc. A good facility should not have a problem with including you in the rehab experience. Do not feel afraid to speak up if

you do not agree with something or wonder why they are doing something. They should not have a problem answering your questions. Remember, you have the right to ask questions and they should not have a problem with answering you. This is a terribly difficult time as it is and you do not need the extra stress of trying to work with a rehab facility that will not work with you or answer your questions.

If you have an insurance company that only pays for a certain facility and the facility is giving you problems then complain to the insurance. You pay monthly premiums, so you deserve satisfaction. Some of your HMOs are unbelievably hard to work with, but you still have the right to complain. If you do not get satisfaction from talking to them then find out what office or agency in your state governs insurance and go to them with your complaint. If you cannot seem to get help anywhere do not be afraid to go to the state attorney's office or even one of those investigative reports at your local TV news station. You might be surprised what can happen when you get one of them involved. Do not feel you are stuck in a bad situation with a rehab center that is not living up to their end of the deal. Rehab is too important a part of the recovery process to accept unsatisfactory service.

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