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## Safeguarding dignity

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# Safeguarding Dignity: A Stroke Survivor's Story

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## Abstract

A stroke can happen at any time to anyone. After a stroke, or cerebrovascular accident, the level of recovery will vary from person to person. Gwen suffered a stroke and has partially regained use of her body. Her story is so inspiring that it should be heard by all. This is Gwen's story recalled to assist the public in the understanding of the human experience. Gwen shares her trials and triumphs in this article. She recalls experiences that were trying, but she faced them with utmost strength and determination. Safeguarding the dignity of a person with a disability is of utmost importance. As the reader will see in her story, it is the right of the individual, the ethical thing to do, to treat all with respect while safeguarding their dignity.

### **Safeguarding Dignity: A Stroke Survivor's Story**

It can happen to anyone at anytime. A stroke, known to professionals as a cerebrovascular accident, can occur without warning. According to the National Institutes of Health (NIH), “stroke is the third leading cause of death and a leading cause of long-term disability in adults,” in the United States (National Institutes of Health, 2010). Approximately 600,000 new strokes are accounted in the U. S. every year. Symptoms of a stroke include sudden weakness or numbness, particularly on one side of the body; sudden confusion, difficulty speaking or understanding speech; sudden visual disturbance in one or both eyes; sudden, severe headache of unknown origin; or sudden loss of balance or coordination, dizziness or difficulty walking (NIH, 2010).

Some people recover fully from a stroke while others are left with a disability; such is the case for Gwen, a woman facing a life-changing event while in her forties. Gwen is now in her fifties and living life with a refreshing conviction. She is paralyzed on her right side, but she manages to stand with assistance. Gwen learned the hard way what it means to be disabled and has suffered humiliation as a result of it. Still, her spirit remains uplifting. It is important for others to hear Gwen's story and to understand that each caregiver, friend, or family member has the opportunity to help a person with a disability maintain their dignity and not suffer loss of self respect.

Most people take for granted the ability to carry out acts of daily living. Society protects the rights of people and focuses on ethical treatment, but what about that place which has never been considered? The place where a person with a disability attempts everyday acts? Whose responsibility is it to provide a voice for the person with a disability? In order for the public to fully understand the daily plights of a person with a disability, Gwen willingly shared her story

of recovery from a massive stroke. But Gwen is in many ways like others who have a disability. Although Gwen's disability resulted from a stroke, disability can result from accident or illness, and the degree is wide and varying.

In the face of a disability, personal dignity is threatened. Wadensten and Ahlstrom (2009) found people with a disability struggled to maintain personal dignity. Even the best intended person who assisted with daily tasks was a reminder of his or her disability and threatened the person's integrity. Disease or accident can leave a person at risk, and "some neurological diseases have multiple consequences, affecting mobility, the sensory system, and often perception and intellectual abilities" (p. 461). As in the case of Gwen, the stroke left her with multiple issues. Her sensory, physical and mental abilities were all affected.

The Americans with Disabilities Act (ADA) concluded "disability is a natural part of life" for everyone, a part of life to prepare for now (Kennedy, 2002, p. 281). The treatment of the person with a disability has changed throughout the years. Forty years ago, a person with a disability might have been institutionalized. Today, elderly citizens with a disability are often separated from society and placed in homes, hidden away from the world. This separation creates a loss for the population. Monetary gain drives the nursing homes, assisted living homes, and retirement villages. Has society failed to protect the dignity of the elder disabled person by encouraging the institutionalization of elders who might live better at home? Is their dignity affected?

Kennedy (2002) said each case of disability is different. The way a person becomes disabled is important. Disability from birth is different from a sudden disability in a functioning adult. In any case, "a loss of independence and dignity can be devastating, but it isn't inevitable" (p. 281). Knowledge, preparation, research, and technology can make a difference in a person's

life while living with a disability, but it is control over one's life that is most important. As a caregiver or family member, "one must ensure that the individual is respected and included in the discussions and decisions that need to be made" (p. 281). Allowing control of self will allow dignity to remain.

Participants in a study by Wadensten and Ahlstrom (2009) thought their integrity was lost when "they were not treated as competent adults" (p. 759). Individuals with disabilities should be empowered to make their own decisions as much as possible to "enable them to maintain their self-esteem and dignity" (p. 759). Without ensuring this personal control, dignity is easily damaged. In Gwen's story, she struggled to maintain her dignity and achieved that goal. She suffered a stroke, but the stroke did not take her dignity; she fought for it. Gwen tells of the ups and downs, the successes and fears, and emerges our own hero.

### *Foretelling*

There is this problem in my family, an issue of early health problems on my father's side. The illness does not favor male or female but blooms inside the body and wreaks havoc at will. I am not sure how far it goes back, but my grandmother died right after she gave birth to her third child, my father. It is an odd thing to know you are going to die; but, she knew. Her physical health deteriorated while she was pregnant with him; they put her in the hospital to try to keep her alive long enough to see her pregnancy through to term. She had only a few days with him before she died.

I cannot imagine how it would feel to be pregnant and to seek safety for your newborn before the event. What is that like to carry a baby, only to know that immediately after birth, you will be gone forever? Knowing you will miss the first smile, the advent of the first tooth, the first steps...seems to be more than is tolerable. My grandmother was strong enough to provide for her

baby boy, my father, even after her death. She asked her mother-in-law to take the baby and raise him as her own. Two days after my father was born, she died.

Pregnancy is difficult for the women in my family. Both my grandmother and her twin sister died after having a few children. My father lived with his grandmother until he was old enough to work on the family farm, and then he moved in with his father, sister and brother, and went to work.

Early on, in his mid 30s, Dad began having health problems of his own. When I was in the tenth grade, he died of a massive heart attack. At that time, I did not realize I would probably suffer some consequences from the family health history. Perhaps my stroke was in the making all my life; but, who can stop the inevitable? When I was young, our family doctor told my parents he thought I would probably never have any children anyway, but if I was able to, I should not. Getting pregnant was not easy for me; however, I was finally blessed to have a baby about two years after I married.

Pregnancy brought new problems. I lost twenty pounds during my first one. After the baby was born, I lost even more weight. The cord was around the baby's neck, yet he survived without negative consequence. I gave birth to my second son about two and a half years after that without any problems...smooth sailing. I even managed to gain twenty pounds during that pregnancy. My third child was born three years almost to the day after my second. It was then that problems with my health really began to surface. My blood pressure went up terribly high during labor with my last pregnancy.

With my last child, my labor was unusually stressful. I remember the doctors and nurses huddled in the corner discussing what they should do with me. If I could teach nursing, I would ask faculty to teach students to make sure someone stays with the patient during difficult times.

From my bed, I could see and hear them, but they did not see me. They were lost in conversation about my dilemma. In my head, I tried to get them to turn around and see me, but neither the nurses nor the doctor noticed my silent cry. I was unable to call for help because the blood pressure medicine had dropped my pressure too low. I could not speak. It took awhile for me to get their attention. Finally, somehow, someone turned around to face me and noticed that I was trying to tell them the baby was coming. I was having the baby while they huddled together trying to figure out what to do; it was happening on its own. The baby was solving their problem.

I came so very close to having a stroke at that time and leaving my three children in the hands of others to raise...but, I escaped it. I am glad it was my choice to have a family; I would not trade anything for them. And grandchildren are a true blessing.

#### *Recalling the day*

The crushing blow hit me without warning and changed my life, as well as everyone's life around me. It was a day just like any other that I had my stroke, a summer's day in 2002. Those days are a vast blankness now. I lost blocks of time, years. Can you imagine such a thing? I had gone out to the car to put something in the trunk with my son. I do not know what happened. I cannot recall any of it. Apparently, while I was bent over in the trunk, something, indeed, did happen. My son struggled to move me up the steps to the house. Finally, he called an ambulance, and I was transported to the hospital. I remember nothing about the vent.

The first thing I do remember was the ceiling of the small emergency room. As I slowly looked around, I felt calm, unsure, and blank. There were two men standing in the corner of the room, and the doctor asked me if I knew them. I looked at them, and replied I thought they were doctors. They were not doctors, in fact, they were my own sons. Like dots on the ocean that cannot be connected, I remembered things in parts. The immediate years before my stroke were

lost. The truth, which I later learned, was that I was not communicating verbally at all, but I did not realize that either. Confusion hid the details from me. Others tell me that I was unable to speak much at all. Only short small bursts of words came forth...meaningless to those hearing them. My family recalls my crying all the time; I was upset at the blankness and the loss of expression in words that hung in my mind. Nothing came out as it was meant to...and simple words were lost. I tried to say hello, and another world would come out of my mouth, slurred and cold. Confusion hung over me and within me. The first week following my stroke, I felt panic. What happened? Why could I not fix it?

### *Recovery*

The confusion lasted for months. It was a long road from there to here. Recovery and rehabilitation were extensive periods of time. I tried to pull memories together, to think things through, but it was impossible at first. Days lingered on in the hospital slowly. It was like rain, the drops never touching each other, but hitting the ground just the same.

Finally, I was discharged from the hospital. The surprise was that I did not recognize my home as we pulled into the driveway. If I had ever lived there, it was unknown to me. The house I had lived in for years was now new to me. My memory stopped at the house we had before this one many years ago. In my head, I thought we were going to the house I had lived in a decade ago. It was like having things you never knew you had, and now suddenly, they were yours. Fright did not enter my mind as much then; I did not know enough to be frightened. My family said I was short tempered, angry at times. I did not remember what I had forgotten, if that makes sense. That blank place was there; but the huge amount of loss was not obvious to me.

As I lay in the bed, I spent hours trying to remember the alphabet and the correct order of numbers. There were letters and numbers missing...simply gone. Why did six not follow three?

Everyday I would find myself saying the alphabet and counting. I would skip numbers and letters, there was no realization they were ever there. It was the oddest thing. Eventually, I could say my alphabet and count, but it was a relearning process. My address was even foreign to me; I had to learn once again where I lived. Family members told me my speech was very slow, and I was still using the wrong words during the first month or so. It was the second month after my stroke when things began to clear some. My personality was edgy as I struggled to gain some control. The stroke had changed my temperament, although I did not realize it. My family never argued with me when I requested something or gave directions. Certainly, I did things differently than before the stroke, but I did not know. They avoided confrontation.

Odd as it may sound, before my stroke, I suffered what the medical community referred to as anxiety attacks. My heart would beat wildly, exhausting me; it did not matter what I was doing at the time. Prior to my stroke, I took Xanax for panic attacks. After my stroke, the panic attacks stopped. I no longer needed the medication. The stroke seemed to remove my panic attack memory. If I could not remember that I suffered from panic attacks, then I seemed to be free of the experience.

### *Forward and Back Again*

My progress was slow. Months passed into years. My speech improved; I could now converse freely. I began to remember more things. My entire focus was on my stroke, and I repeated the phrase “before my stroke” with almost every comment. My family said I tried to live within that period, the pre-stroke period. It was several years before that changed.

Somewhere during the years before my stroke, I suffered a heart attack and had stints placed in my heart. I recall little of that. Vaguely, I recall having surgery on my back for a crushed

vertebra. My husband recalls that as being my most painful experience. Somehow, I do not remember that either.

To complicate things, I lost all feeling in the right portion of my body. My right arm and leg continually shook all the time. I had lost control. Driving a car would be impossible for the rest of my life...my vision and limbs were affected making it impossible to operate a vehicle. In the darkest of times, I felt lucky, because friends and family members always came to my rescue. There were days I just wanted to go shopping. One particular friend would come and take me. All I had to do was call, although I was careful not to abuse the friendship. She took me to take care of business or to shop.

Eating was once a pleasurable event, but now food had to be placed in front of me in a particular way so that I could see to eat it with my eye, and maneuver it with my good hand. I concluded that since I am picky about my food placement because I could not see, I should stay off the road and not risk another's life by driving. In fact, travel for me had become a whole issue in itself. I could not easily get in and out of a car, board a train or an airplane. Everything took special care and effort.

### *On The Road Again*

When a person is disabled, like me, it is much more convenient to get on and off flights through terminals with plane connectors than to go outside and climb steps up to the plane door, which I cannot do anyway. People with disabilities do not proceed in a normal fashion for boarding any mass transit form. When I am being ushered around, I call myself "little old lady." That is not really true; I am a middle-aged woman with a disability.

Magically, I am there one moment and gone the next. One second I am in the airport and the next sitting in the airplane. As a regular passenger, you will not see me board or exit the

plane. Everyone is in a hurry to get to their destination. There is really no time for regular passengers to hang around and see what they did with the wheelchair lady.

Larger airports are much easier for me. Regular passengers travel from building to building on an electronic trolley system that makes brief stops at each gateway connecting area. The little automated voice always lets you know where you are at each stop. I use the trolley to get to my next destination, to go to the restroom, and maybe even to get something to eat. Of course, someone has to help me get on and off the trolley as my one leg often is not fast enough to move me safely. My name is called over the loud speaker before the other passengers. I am boarded before everyone else. I wonder if people think about the magic of it all...the seeing me in the terminal and then in the airplane seat faster than lightening?

Boarding is not quite as simple as it once was for me, even with the magic. I sit in the wheelchair with a folded one-handed walker around my neck; my leg and foot are braced. Because of my vision loss, I am not sure if they realize I cannot see well. I am always worried I will bump into someone. Most people probably never consider what a person sitting in a wheelchair sees, at least not until they ride in one. From my chair, hurling through the crowded airport, I look up into mostly smiling faces. Faces are not eye level when people are pushed together, and I am sitting low in wheelchair. People do not see me until they are standing in front of my knees. When using my walker, I look down. There is always the risk of falling.

I wonder what people think when I am taken from the long line and boarded ahead of them. Once on the plane, I am placed in a small wheelchair, without sides, at the door. Although not overweight, my hips hit the seats, bump, bump, as I am pushed to my seat. It's a small chair that fits easily between the tight rows. It is much like the narrow food cart that is used to serve passengers peanuts and coke. The airlines are doing the best they can, but a disability does make

you feel different. After boarding the plane, I stand to get into a seat with a one-handed walker which is easier to maneuver in the small aisle.

The one experience I could forever avoid is the use of a forklift for boarding. The smaller planes cannot belly up to the airport, and passengers enter by going up long flights of steps. This is the most difficult boarding of all for me. In order to board small planes, I am loaded onto a forklift in my wheelchair and boarded through the small opening at the top of the boarding stairs. There is no other way, and I choose to travel; but, it is an event that is thought provoking to say the least.

#### *And the Years Were Seven*

Seven years after my stroke, I manage to get around the house, to use the computer, and to go shopping for small periods of times when someone can take me. I am dependent on those who love and care about me for outings. I am thankful to those people. My husband loves me and treats me as his wife; for that, I am very grateful. He is my saving grace in my life. I remain determined and hopeful. Little by little the dots connect, and I can remember things. Today, I remember so much more than I did immediately after my stroke. I focused for a long time on trying to stop the shaking and walk again, but now I am more resigned and at peace with everything. Now, I email friends of my successful brief walks; I will not give up or quit. I am more patient and have a different perspective now, some seven years later. I do not phrase every sentence with the words “before my stroke.” Since the beginning of my life, I have always been preparing for a stroke or recovering from it.

The shattered glass slowly pulls together in my mind, reforming into a pane through which I view the world. I wanted to share my story to tell you what it is like to have a stroke. It is a life changer sometimes. And, if you see a lady in an airport in a wheelchair wearing a folded

walker around her neck with her foot in a leg/foot brace, it might just be me...just smile or say hello. Remember, if I do not reply, I do not have very good vision now and may not see you; but, do not give up...I never do! I am like an old Timex watch, I have taken a licking and keep on ticking.—Gwen

Gwen lost control during certain times in her life. Caregivers inadvertently failed to consider her feelings and wishes. In stressful childbirth labor, the nurses and doctors talked among themselves but failed to turn to her and consult her about her own body. She wanted presence from the caregivers during her trying labor, but did not receive it.

The frustration that came with loss of memory and ability to do simple, familiar tasks was seen through what her family called her short temper. The inability to remember what was forgotten and the blank spaces created a change in her. She lost control for awhile. She recalled her personality as being edgy as she tried to gain control. Her family avoided arguing with her and did not respond angrily. They realized she was fighting for some self control, and they allowed her to have that control by avoiding confrontation. They allowed her to maintain choice and dignity.

Gwen lost the ability to drive, but her friends and family were there to support her. She lost the ability to feed herself but did not give up until she could once again accomplish the seemingly simple task. Things change with a disability. Simply boarding a plane became a special event. Boarding is not normal for a person with a disability. Boarding is anything but normal for a person in a wheelchair. Gwen was not in control of her boarding, but instead whisked around as if by magic to the plane.

Her words echo the truth. She is not a disability, but instead she is “a middle-aged woman with a disability.” Choices are made for children but not always required for adults who have a

disability. Choice is important to maintain dignity. Magic acts are for children; maintaining independence when possible is for adults.

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