Betty - From Ambitious College Girl to Coma Survivor

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I have been doing brain injury representation for over 20 years, and there are times I swear that the condition is contagious. Of course it isn’t, but it is such a prolific tragedy, that as soon as your attention is drawn to one TBI tragedy, you will soon become aware of another.

Betty’s story is just such a case. One family’s coming together to deal with a motorcycle accident was the only reason that Betty’s was in the wrong place at the wrong time. The accident was November 24, 1982, yet that irony had never occurred to Betty until we asked her about it.

I was in a car with a fellow student from Loyola University, and she was driving 68 miles an hour and drove into the back of an 18-wheel truck, and I sustained a traumatic brain injury.

As we said in Angela’s story (http://tbivoices.com/angelaccontents.php) and will say often on these blogs, these stories aren’t about the reckless/negligent behavior that causes these tragedies. Traumatic brain injury can happen in an instant, regardless of fault. Yet when there is outrageous conduct involved, it does create another layer of grief for the survivor to dwell on.

A girl in the dental hygiene program asked me if I would go home with her for Thanksgiving vacation. The odd thing is I had called my parents the week prior asking them for recipes because I told them that I was going to be staying in my apartment and all of a sudden she tells me that her brother had been in a motorcycle accident and asked me if I would go home with her to spend Thanksgiving at her mother’s house.

So I agreed and I didn’t realize when she picked me up that she had already been drinking and she had a rather high blood alcohol level the police tested her with when the accident occurred – .28

Click here to view: http://youtu.be/oEBZ0nLvra4

The thing that bothers me is I did go to see her. My mother and I went down to New Orleans to pick up my sister, Jane from Loyola from college the following May and she took me over to this girl’s apartment. All I wanted to hear were two
words come out of her mouth, I’m sorry, and she couldn’t do it. I emphatically asked her what happened and she lied through the whole thing.

That simple choice to seek company on Thanksgiving was a life changing fork in the road. Betty suffered a severe brain injury in the crash, including frontal lobe (a subdural hematoma) and occipital lobe injury, requiring brain surgery. Her accident happened near Hattiesburg, Mississippi, where her brain surgery and treatment were given. Five weeks later when she was air flighted back to Froedtert Hospital in Milwaukee, she was still in a coma. She was paralyzed for two months.

As would be expected, she has a long period of amnesia, both retrograde and post-traumatic amnesia, beginning weeks before the accident and not ending until near the end of her inpatient rehabilitation. As Betty says:

“There are days in November I remember… But I remember being in Sacred Heart Rehabilitation Hospital” Her accident was November 24 and Sacred Heart was the third hospital she was in. She was hospitalized for almost three months.

Betty - The Impact on the Family of Waiting Out the Coma

One of the common denominators of all coma cases is the shock of the phone call to the family. Our page http://waiting.com written in 1997 begins with these words:

“You have a phone call”

Perhaps what grabbed me so much the first time I heard Lethan’s story, “Who Am I Again” was the voice of his mother, with eerily similar words, her remembering to take the dog out before she rushed to the hospital. I am always touched by that voice, even when it is coming third hand as it does with Lethan, as it does with Betty. Betty tells about her parents vigil:

Both of them got on a plane and flew down Thanksgiving Day. My father, who is a dentist, stayed in Mississippi with my mom for approximately a week or a week and a half and then he had to come back up to return to work and my mother slept on a cot in my room or in another room in the hospital the whole time I was there.

It is clear that the fork in the road choice that put Betty in that car, has caused her father considerable heartache.

I’m particularly close to my dad and a few years later after my injury my dad said that he had woke up that morning and he felt – had a sick feeling and he had gotten an emergency call so he had to go to his office. Immediately he tried calling me to tell me not to go to Kim’s mother’s house and by the time he got through my roommates told him that I had already left. So he was the one that answered the phone when the neurosurgeon called.
Clearly those questions of fate trouble everyone who has spent time in an ICU waiting room, yet reversing the order of things would not eliminate tragedy just shift it. Events are set in motion by each little choice that any of us make, all of our destinies intertwined. The only blame lies with those who acted without due regard for the safety of others because those choices are an invitation to tragedy, a tempting of the Gods of fate. Thus as we keep in our hearts the permanent tragedy of traumatic brain injury, the immediate and long term grief of those who have waited is always remembered.

Click here to view: http://youtu.be/wqfxCG2hVy4

**Betty - Rehabilitation Begins from Coma, Subdural Hematoma**

While Betty was receiving some type of rehabilitation at each point of her recovery journey, even while still in a coma, her recollection of that begins towards the end of her three months of inpatient stay. After discharge, she went to outpatient therapy at Curative Rehabilitation, in Wauwatosa. Her therapy was in four basic areas, physical, occupational, speech pathology and psychology.

She says the therapy was:

> Quite intense some of the work that I had to do there especially in speech. The speech pathologist would say cut a newspaper from – cut out an article from the newspaper and then write a summary and one of the problems I have is I am, I am known to confabulate and add on a lot and I would try to write a synopsis of a story and it would be a whole page long and that’s not exactly what she wanted so I had a problem following directions and speech pathology was one of the difficult sessions that I was in when I was at Curative.

Click here to view: http://youtu.be/kVmkqUVvTDA

Her problem with confabulation is an extremely common problem in severe brain injury survivors. So much of therapy, life, is a puzzle in those early months and the brain doesn’t like a puzzle with missing pieces. The solution is to cram pieces into the puzzle, but they rarely fit. Yet the incongruity of the pattern is often missed by the brain injured person.

As Betty says:

> Somebody tells me a story; next thing I do is I like to add things on and make it more exciting and they’re not true facts.

Lethan’s first memory was of an elaborate series of adding things on to the concert in his room with the rock band Fish. At least now, he realizes he was “making up” a story.

Click here to view: http://youtu.be/hLCdWalig_k
Betty - Severe Brain Injury Comes with Physical Disability

Brain injury, brain damage is thought of as a thinking disorder, a problem which effects memory, concentration. But the brain controls everything that we are, how we move, how we breath, the mechanism of speech, vision balance. how we feel, all of our senses. Coma and severe brain injuries are often followed by severe physical limitations and the need for intensive physical therapy. Betty was one of those cases.

I was paralyzed on my left side for approximately a month and a half. I also had an eye injury. I know mom took me to the eye institute a couple of times but in physical therapy it was a lot of bending and trying to utilize the arm to get the muscle back to operating function. I know I’ve got a minimal left-sided weakness and I’ll have that for the rest of my life. I know that’s there because I can tell but it’s something that I work around and when I exercise I just try to do the best I can with the exercises that I’m able to do.

I had four years of outpatient therapy at Curative and also in the hospitals when I was able to stand up and start walking the physical therapists were working with me frequently on being able to move and operate my body in the proper way.

Click here to view: http://youtu.be/J_WIzIsu3Gg

Betty was sitting throughout our interview, so that left sided weakness is not obvious on the video, but an experienced eye would no doubt see it in her gait, the way she carries herself. If you have seen Lethan’s “Who Am I Again”, you will not forget his heel toe, heel toe, demonstration. Betty has similar struggles.

I carried myself a little differently because of the left-sided weakness that I had. I didn’t have to wear a brace on my leg so I was thankful for that but my walking was not as a normal person walks. My dad and I would go out for walks when the weather was nice and the big thing I had to remember was heel, toe, heel, toe and all of a sudden if my feet started to hurt I’d just remind myself that I got to go back to heel, toe, heel, toe when I walk.

Click here to view: http://youtu.be/_4x096ttRJU

She also suffered visual and balance problems in the wreck.

Click here to view: http://youtu.be/NrvlKrlt1d8

People think of “seizures” as the profound shaking and foaming at the mouth that does occur with a grand mal seizure and such seizure is a significant risk from a coma injury. Yet seizures come in many other varieties as well, including what are called “absence spells” where a person seemingly fully conscious and aware, loses time, gets lost confused, with no recollection of what occurred. See
That has happened to Betty, although not with the frequency it did in the early years of her recovery.

I might be just sitting by myself in my family room and three or four minutes later I’ll look at the clock, oh, I should be making dinner now. Then I get up and do what I have to do. Yeah, that has happened from time to time.

See also [http://www.epilepsy.com/epilepsy/seizure_absence](http://www.epilepsy.com/epilepsy/seizure_absence)

**Betty - Speech Pathology and Occupational Therapy**

Perhaps because historically the speech issues after brain damage were among the most obvious, much of the hardcore cognitive rehabilitation after severe brain injury falls into the gamut of speech pathologists. Betty received both speech and occupational therapy. She particularly liked her OT.

Occupational therapy, that was, that was one of my favorites because I loved working with clay, making bowls. I did cross stitch, a lot of other projects I did when I was in occupational therapy that helped eye-hand coordination.

Betty describes a love hate relationship with speech pathology, hating it because it reflected the image of her deficits so clearly to her, but now so thankful for the level of care she got.

I hated it but I love – I hated it but it helped me. I felt that I was being treated as an 8 year old and I didn’t, I, and I didn’t feel that I needed it. I – well, to this point I still don’t see fully my deficits but it’s something I have to live with.

She describes her speech therapy:

First off, she would have me – she would bring in a book, you know, a simplified, like a grade school book and have me read it and I would read that and try to figure out what was going on in the story and sometimes I would get confused even though it was a simplified story. But we would stop and then the speech pathologist would say well, what just happened and if, if I needed to I would write it down so I would have a note of it and then we would continue on in the story. And then by the end of the story we would put it altogether and we’d have a synopsis of what I had just read but that was something that I needed help with and writing those two papers for school was very difficult and the speech pathologist helped me immensely on that because I would go from one subject to another without any continuity in what I was writing.

Click here to view: [http://youtu.be/gzwwy_d2zoA](http://youtu.be/gzwwy_d2zoA)

It was through speech pathology that Betty learned the skills to reintegrate herself into the outside world.
Well, it’s – she did not – she didn’t treat me mean or was nasty to me but it was something that she had to go to get my brain working or operating in an adult level and it’s something that I needed to do and some of these exercises I thought well I did these way back when. But when I started doing them I found that I had difficulty and then at that point I was able to tell her I’m having trouble with this, could you help me? And I think that opened up a big door because at that point she knew that I was open to change and open to the help that she was there to give and I think that improved my rehabilitation and my cognitive thinking immensely.

*And without speech pathology:*

I would probably right now be at my mom and dad’s house collecting disability, probably doing nothing.

Click here to view: [http://youtu.be/Zb4-byZ9GZU](http://youtu.be/Zb4-byZ9GZU)

Speech pathology and other disability assistance helped her complete her last semester of college. With professional assistance, she persevered and obtained her diploma. Such was not an easy process, including being asked to leave one program. She asked the professor so many questions it became clear she wasn’t understanding the curriculum.

I was already a licensed hygienist as I said in Wisconsin and Louisiana and I had just general curriculum 12 credits to complete and I started out at Cardinal Stritch, was there for three weeks and the instructor called my mother and asked to take me out.

I needed a lot of help. All the classes I took I was given help. As I said I started at Cardinal Stritch and they asked me to leave so that was kind of tough. I was disrupting the class a lot. I kept asking a lot of questions and the teacher just felt that I was not understanding what she was saying.

I was released from the hospital the end of January. I would say the following September was when I went to school. My mother did take me out to WCTC or it was WCTI at the time. It has a big special needs department and I worked with two instructors in there.

I had two 5,000 word papers that I had to complete for Loyola. One was on John Dunn. I don’t remember picking that subject, John Dunn, and the other one was on retail store franchise dentistry which was just starting back then in 82. So they also helped me write those two papers.

I never went back to New Orleans except I did get permission from the dean of the school to complete the bachelor of science classes that I needed to take. I got permission from the dean to complete those. I completed them up here at UWW and they have a big special needs department there and then in 1986 my mom and I flew down to New Orleans and I picked up my bachelor of science degree.
Betty - Returning to Work After Severe Brain Injury

Betty received intensive vocational rehabilitation for nine months, which included more work with a speech pathologist and enrollment in a dental assisting program, even though she was already a license hygienist. “The problem was I knew almost more than the teachers knew and so that was difficult for me also but I got through it and I finished that program.”

Click here to view: http://youtu.be/2pP9RohwRKk

Once Betty had finished her voc rehab, she was able to find work as a dental hygienist, but surprisingly, her first job was her easiest and it got progressively harder to stay employed after that. She made what was likely a brain injured mistake in quitting her first job. Jobs got harder to keep and when she did find one with some longevity, she quit that again.

I stayed for four years at that position and not a good idea on my part but I quit and then from then on I looked for another position and in between I had been terminated from two or three other places but then I found a, a dental hygiene job on South 27th Street and I stayed there for four years and then I just decided I had had enough of the office and I left and probably my biggest mistake so far.

For anyone to maintain employment, they not only have to have the skills to do the job, but also the appreciation that work is work, and that a good job may be irreplaceable. That is far more difficult to remember, when judgment, mood and initiative is impaired after a brain injury.

However, Betty had another problem. She had already known how to be a dental hygienist before her accident and after rehab, was able to do much of what was required of her because it required her to use skills she had learned before her accident. But the field of dentistry, like any profession, changed, she couldn’t learn the new techniques, acquire the new skills to adapt.

Especially with taking X-rays. I mean I had taken the class. I had passed it at Loyola and coming back up here all of a sudden they say we’ve got these new X-rays. They’re digital. This is how you do it. They’d show me once and then I would forget and I’d say could I write this down and they would say oh you should be able to remember this and it was just very difficult for me to remember how to put the X-ray – you had to put the X-ray in the mouth perfect – and the X-ray had to go in the mouth in a perfect form and I could take the X-ray but putting it in the mouth and getting it in the proper form in the holder was something I had a difficult time with and I couldn’t remember how to do it.
As I said, I remembered – I’m grateful I do remember my dental hygiene work and I can do that and I can do that well but new dental – I mean the dental field changes all the time and all these new aspects that come in are difficult for me to learn and to implement in my work that I’m doing. I mean, I, I know how to use the scalers, I know how to use a Cavitron but all of a sudden now there’s all these other instruments and things that you have to operate with electricity that I don’t have – that I sometimes I forget how to operate them or work them.

Any plan for vocational rehabilitation following brain injury must take into account not only the simple issues of preparing the brain injured person to the workplace, the work environment as detailed by Angela, but must also factor in the challenges that the brain injured person will have in learning new things in the non-structured classroom that is the workplace. For Angela’s workplace problems, click here. Further, any successful program must constantly reinforce to the survivor the value of a job when they find one and progressively harder task of getting a replacement job.

**Betty - Cognitive Challenges: Sequencing, Staying on Task, Topic**

Those who don’t know much about brain injury are often surprised at how “normal” someone with a brain injury may be. Only the truly profoundly injured will show the kind of overt dementia that we have been programmed to expect. Most cognitive challenges are far more subtle than what an Alzheimer’s or severely learning impaired individual might have. Much of the brain may be unaffected by even a severe injury, including long term memory and communication ability. Both Angela our first case study and Betty are perfect examples of that. That Betty communicates so well is both proof of that tendency but also a credit to the extensive and multi-year rehabilitation that she received post injury.

Betty describes a number of classic cognitive problems. Sequencing (putting things in order) and memory are ongoing problems. Like most survivors, she has learned to write everything down.

If there’s something I need to do or something I need to get from the store the night before I’ll write it on a list and I’ll place it on top of my purse so that when I come downstairs and see it then I know I’ve got to go to the store to get those items.

Driving is one of the most troubling aspects of disability for a wide range of brain injured individuals. It is a uniquely cognitively challenging task, requiring intense attention, visual perception, multi-tasking, capacity to deal with stress and coordinated sensory, reflexive and muscular control. It took Betty about three years to get her drivers license again after her TBI. Even now more than 25 years post injury, she must be careful where and when she drivers.

I don’t like to drive distances too much. I have a friend who also sustained a head injury who lives in south Milwaukee and I’ve gotten lost trying to get over to that
house at least a dozen times. That’s a problem I have is somebody gives me directions, I’ll look at the directions and I think that I’m following them and all of a sudden I’m in, practically in Illinois. I use a lot of gas when I’m driving, it’s a sad situation.

Click here to view: http://youtu.be/xQKmzaG3yvg

Fatigue is not as big of a problem for Betty as for some survivors, but she does find that lack of energy does make it more difficult to complete her household duties and to stay on task.

I get very tired, and with me not working now there have been times that my husband would get up, he gets up at 5:00 three mornings a week and goes to the YMCA to work out and then he goes to work and I get, well I get up with him but then I go right back to bed and I would set the alarm for maybe 7:30, 8:00 and it goes off and I, oh, I want to sleep another hour and that doesn’t do me any good because I know I’ve got things that I have to do with the house and shopping or laundry or going to see my mom, helping her out. It’s just a difficult, it’s a difficulty I have putting that all together and knowing what I’m supposed to be – keeping my mind on one task, my mind on, keeping my mind on task for the one particular action that I’m doing.

Click here to view: http://youtu.be/3mI040krI6o

She also has significant anxiety problems in keeping up in conversations.

Sometimes if I walk into a conversation and somebody would start talking to me immediately and I’d have no idea what they’re talking about I would feel not very smart asking well what was it that you were talking about? And if it’s a subject they’ve been discussing for 15 minutes and my brain walks away and I come back and then oh what was that you were talking about? Then they think that I’m not paying attention.

She also has a hard time staying on topic in conversation. She explains:

I seem to jump from topic to topic. I’m sitting with a couple people and they’re talking about how one time that they had gone on a trip and they lost their luggage all of a sudden I’ll click in and I’ll say oh well I went to college in New Orleans and I flew down there a couple times I just – I mean, it has nothing to do with what they started talking about and then they look at each other as if to say okay why did she just do that. Because they had been talking about one thing and I inappropriately at times also change subjects and say things that are not appropriate.

Click here to view: http://youtu.be/aZxGcwHbVrc
Betty - Frontal Lobe and Executive Functioning Challenges After Coma

Betty suffered a subdural hematoma in her frontal lobe injury, requiring brain surgery. It is in her frontal lobe functioning that she shows the most significant ongoing deficits. Her frontal lobe deficits include social and emotional issues and executive functioning problems. Certain aspects of all of the issues we have discussed previously relate to frontal lobe injury, such as her challenges in conversation. She also has problems with impolitic speech, impatience and independence. She talks too much about her own TBI, particularly in social settings where that much familiarity isn’t appropriate. Her inability to make even small decisions can cause her brain to overload, then shut down.

“Executive functions are the neurocognitive operations that enable purposeful behavior as it unfolds in time.” Evaluation and Treatment of Mild Traumatic Brain Injury” Varney,Roberts, page 133. The executive functions relate to three primary purposes, goals, organization of time and flexibility.

- 1. A person or organization must be able to set goals;
- 2. Likewise, in order to achieve those goals, a person or organization must organize how time and effort are allocated to a plan; and
- 3. An person or an organization must have sufficient flexibility to shift the methods of enacting the plan, when change or miscalculations require it.

Think of the brain as the quarterback of a football team. The team has overall goals of winning the game, going to the playoffs, winning the Super Bowl. The quarterback has smaller goals on each play, each drive. Prior to the game, the coaches of the team will create a game plan, to achieve those goals, with each player assigned his tasks, in temporal sequence, to carry out the game plan. But ultimately, the success or failure of the short term and long term goals, will depend upon the ability of the quarterback to implement the game plan. Even if all other parts of the team are working fine, if the executive of the team (the quarterback during the game) is unable to coordinate all of the various activities of the other players – in time sequence and with the flexibility to change the play – the team will fail.

The team that can’t make a plan will fail. The quarterback who can’t coordinate the time sequence of his other 10 players in carrying out a play will fail. The quarterback who can’t call the audible, will fail.

Some of Betty’s challenges fit neatly into quarterback analogy. But the frontal lobes also control behavior, emotions and are where we learn to become adults. Becoming an adult requires a generation long inlay of subtle social cues, inhibitions and development of independence upon the cerebral cortex of the brain. Subtle damage can set back that process for years. Significant damage can not only erase the neural networks but eliminate the neurons upon which a new set of social mores could be imprinted.
In our next blog, we will elaborate upon the particular frontal lobe deficits Betty identified in her own behavior.

**Betty - Particular and Frontal Lobe Challenges After Severe TBI**

Betty, like most severely brain injured survivors has issues with impulsivity and impolitic speech. She just doesn’t know quite when not to express exactly what is on her mind. She gives the example of how, at least from her perception, she ruined Christmas.

   My husband and I went to his ex-wife’s Christmas morning to open up Christmas gifts and she handed me a gift and I opened it up and it was a plastic popcorn popper. I looked at it and I kind of made a smirk and I said, “you gave us this last year.”

Click here to view: [http://youtu.be/JEQB33SZkgU](http://youtu.be/JEQB33SZkgU)

   I dance to the beat of a different drummer. I guess, well the only way I can say it, I see things differently than a lot of other people see things and when I act upon something I act upon it as I feel I should and sometimes it’s not appropriate.

Click here to view: [http://youtu.be/iLyFUYjpDYg](http://youtu.be/iLyFUYjpDYg)

Similar to her problems with impulsivity, she has difficulty with patience. She said:

   When I’m in occupational therapy and I’m looking on, working on a big cross stitch project, I’d look at it and I’m halfway finished and I get angry because I’ve done stitches wrong and I have to go back and take ‘em out. I used to try to cover ‘em up, which was not a good idea, and I’d take it into therapy and she’d say, we have to take all this apart and you have to do it again. And then I would get angry at myself for allowing myself to just slop over the problem and think I can fix it in the wrong way.

Click here to view: [http://youtu.be/Maq9BfypV7c](http://youtu.be/Maq9BfypV7c)

Betty has classic problems with making decisions. Deciding what to wear can take an inordinately long time, as can deciding what to make for dinner.

   I have a hard time with dinner making decisions, what am I going to make for dinner, what am I going to, what ingredients do I need to make this product, decision makings like when I go to the bank, how much money should I take out from the checking account and then I just stand there and the woman would say, excuse me but we’ve got somebody, you know, behind you, if they can go in front of you please, let them go first.
Shopping is no better:

Let’s just say I shop a lot with my husband now because he’ll tell me to get something, I’ll go to the store and I’ll see this item, this item, this item, this item and I’ll come home and I didn’t get what he wanted me to get, which makes him –

Like let’s say if he wanted deodorant, I’d go in I’d go, oh we need some Pepsi Max, I’ll get some donuts for Saturday, I need eggs and then okay that’s it, and I’ll leave, forget the deodorant.

One of the hardest things for brain injured people is to regain the maturity to live independently. As Betty said earlier, she didn’t like being treated like an eight year old but recognizes that was the level she was on in some ways during her rehabilitation. Betty believes that because her parents (unlike many therapists)expected her to behave like an adult, she did learn to take care of herself and was able to live somewhat independently.

What basically happened is my mom said she never acted like this before she was hurt and she’s not going to act like this in my home, in our home. And she, my mom was a very strict disciplinarian and I’m grateful to her and thankful to her for all that she helped me accomplish. And the insight that I got from my father as far as relationships and being able to talk to people and react in appropriate manners, I learned that in therapy and at home.

Click here to view: http://youtu.be/2rekjOTqkqw

I have seen many other examples of severely brain injured people relearning to become adults much more easily from parents. Being scolded, ordered around, having expectations placed upon you is much easier to take from mom than from a spouse, a friend or a co-worker. The firm hand of a parent is a familiar thing, even after a TBI.

**Betty - Dating and Relationships After Brain Injury**

Betty’s relative success in regaining her adulthood is verified by the long term marriage she is a part of. But to go from college girl to rehab to the dating scene is a difficult transition, one fraught with peril. Alcohol, not knowing who to trust and impulsivity made dating unproductive. Most of it is too personal to post publicly, even in a forum with some confidentiality. Her mother and father helped her through it and then almost 20 years after her accident, she met her husband.

Her father was particularly helpful with the long wait:

I’d be so upset because everyone else in my family was married and had children and he would look at me and say just wait, if the time for you is going to come it will come when you least expect it. So at that point, I was probably 45 or 46 at that point after dating a bunch of knuckleheads, I went out one night with some
friends and we were having a good time, we were playing some cards and then everybody was getting ready to leave and as they got up to go I was the last one to get my coat and I’m walking out and all of a sudden this young man says, hi, would you like a soda? I thought wow, because I had been staring at him a little bit.

The relationship started well but when Betty started having some difficulty, she decided that he wouldn’t be interested in someone with her problems, so she stopped calling him. Fortunately, her brothers convinced her to give the relationship one more try.

I told them the problems that I had and both of them told me, they said probably on Monday while he’s at work call his apartment and just tell him that you’re sorry for what had happened and that if he’d like to talk that you’d be willing to talk to him. And well he called me back and we started talking and going out again, we ended up getting married that June, no the following June.

When asked if he had been surprised about some of her challenges after they got married, she explained:

I never realized this until a few years ago. My mom actually took him aside and gave him an opportunity to say he didn’t, like maybe he did not want to participate, or did not want to go through with the wedding because she told me deficits and problems that I would have and he listened to her, and he told me later he said your mom told me this would be a problem. And I said, and ”You still accepted?” He said: “I love you for who you are, so.”

Click here to view: http://youtu.be/xn18nHs8Lac

Betty - Maximum Recovery from TBI Requires a Lifetime of Care

One of the consistent themes of TBI Voices will always be that brain injury does not get better in a month, a year, but requires a decade long or more commitment to improving. Larry, one of Lethan’s characters in “Who Am I Again” was in the rehab hospital a decade after his injury. Betty has been 28 years since her accident and received the top level of care, that went on for years. Yet she describes herself as improving still.

I see myself having improved greatly and one of the biggest things I keep in my mind is I’m open and I look forward to improving even more. So the deficits that I do have now, you know, as far as memory, I remember, I, I mean I keep a date book with me at all times, I used to be very upset that I had to write things down, but now I keep it with me and if somebody says are you doing something next Friday, I can open my date book, see if we’re free.

If I’m on the phone I always have a pad of paper next to me so that no matter who calls I can write it down and write down tidbits of what that person had said
making notes as far as grocery lists, knowing what to do when I get to the store, the specific items I need to buy and stay away from the other items that I would like to purchase. Keeping myself active and exercising, I do that three times a week at an exercise fitness club.

Try to work on my memory. I’m trying to improve, trying to improve my short term memory, my long term memory is basically pretty good but the short term is what I have problems with.

Click here to view: http://youtu.be/TEm-g9QC sak

Betty benefitted from this long term commitment to care. But the insurance companies are winning the battle to strictly define how much care is allowed, TBI rehabilitation facilities are closing and care is being defined in finite amounts, not what is needed to provide a lifetime of accommodation. Betty is concerned that she would not be given the same chances to recovery today.

I believe I was taken care of very well. The people that I would see at Curative, they cared for me. They were all very kind. I don’t know today if – I think maybe one of the problems is well, of course, no one wants to get involved and then they step back and here’s a person, let’s have them move their hands and their legs. And it’s like this is a Social Security number and I got to see this person for a half an hour. I just don’t think there is as much caring and feeling as there had when I had been in rehabilitation.

**Betty - Don’t Ever Give Up After Brain Injury**

Dealing with the grief for what is lost and finding a way to see the hope is perhaps the biggest challenge for any brain injury survivor. Says Betty:

If I couldn’t remember any of (who I was before) and just came out of being in a coma and having to start all over again that wouldn’t be a problem but since I can remember, you know, who I was before I was hurt and the obstacles I’ve had to overcome that’s been difficult.

But Betty’s one of the miracles, a person with a coma that last into the second month, with amnesia that stretched into the third month. She needed brain surgery, overcame paralysis and got great care that last for years. She honestly discussed her difficult times, sharing personal details that others might be unwilling to do. She volunteered to be part of TBI Voices because “I think traumatic brain injury plays a very important part in society today and because people are living. There’s a lot that needs to be done.”

Betty’s voice on TBI Voices is a strong message for hope, and we hope her last words will ring true for all of those who deal with this disability, especially those who are new to the struggles:
I’d like to tell brain injury survivors that first thing is don’t ever give up, just don’t ever give up. In therapy I, there were three people that gave up and it was very difficult. Work as hard as you can and just know that the therapists and the people, the professionals that you’re working with are not trying to take away from you, they’re trying to build up what you already have to make you a contributing member of society and just always keep working and just always hold in your memory that you’re the best that you can be and that tomorrow you’re going to find something else that you’re going to be better at and just continue to improve and always try to keep a positive mental attitude, that’s a big thing too.

Click here to view: http://youtu.be/c8Xb-985iQ4

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