

A FAMILY PERSPECTIVE ON LIVING WITH TRAUMATIC BRAIN INJURY:

An Interview with Rosemary Rawlins

Interviewer: Thank you for agreeing to talk with us about brain injury, changes, and family life for the TBI Today newsletter. Tell us please, how much did your lives change after your husband's injury?

Mrs. Rawlins: The influence of TBI on a family is enormous. We are a close family with a fairly non-descript life - good marriage, twin teenage girls and two working parents. Hugh's traumatic brain injury literally redefined our entire existence in one second flat. The landscape of our lives, our roles in the family, and even the way we structure our day, has all been altered. In fact, the only thing that is for certain seems to be uncertainty itself.

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Interviewer: Tell us a little about your husband's injury, especially the first few days and weeks afterward.

Mrs. Rawlins: On April 13th last year, my husband of 25 years was hit by a car while riding his bicycle. A seasoned athlete, he had worn a helmet. He was rushed to MCV via rescue squad where he had the finest medical care he could receive. From a physical standpoint, his recovery has been remarkable. He has endured and overcome the loss of his left side as well as multiple cognitive problems. The first three months were very challenging due to his bone flap operation, removal of part of his skull to allow brain swelling to recede. He had a soft spot on his head and had to wear a helmet and gait belt - a strap we had to hold on to so he would not lose his balance and hit his head. During this time his memory was seriously impaired. He spent just over a month in the hospital and on his last day there, when a doctor asked him, "Mr. Rawlins, do you know where you are?" he answered with a quizzical look, "In a government building?"

Interviewer: What were things like when your husband first came home from the hospital?

Mrs. Rawlins: Hugh required the care of a night sitter so my daughters and I could sleep a few hours without worrying that he would wander, fall or leave the house. This expense was not covered by our insurance. He slowly improved through extensive full day rehabilitation at HealthSouth in all therapies: occupational, physical, psychological, speech and group therapies. As he recovered and improved, we celebrated. We constantly looked for signs of the man we used to live with. He was elusive. He would appear, then slide back into a staring zombie state. He would smile his old smile, then quickly fade and fall asleep frighteningly fast. We knew he was in there and slowly coaxed him out with lots of affection and loving care. Each familiar encounter was precious to us.

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Interviewer: A lot of people say that brain injury affects family life especially in terms of relationships between parents and children. Do you think that's true?

Mrs. Rawlins: We have gone from a family of two fit parents to one disabled parent and one weakened parent (due to exhaustion and stress). Our children have had to grow up fast. Their needs, once the central issue in our family, have been put aside or on the back burner at times. Their father's needs took over. His appointments, treatments, and progress became the focus of everyday life for many months.

Interviewer: Have your children changed?

Mrs. Rawlins: My teenage girls have vacillated between being children and adults; they have learned to take charge and make decisions. They have looked outside themselves and into the lives of their parents, seeing them as people rather than just parental figures. Their foundation has been rocked but not cracked.

Interviewer: As a wife, how has the injury affected you?

Mrs. Rawlins: I have changed. At times I feel a thousand times stronger and other times twenty years older than my 46 years. I have learned the life lessons that come with the near finality of death. I have experienced the frustration of bureaucracy at it's worst (dealing with insurance companies). I have spent entire days pressing "1" for English and "0" to speak to a representative, just to get the services my husband needs. I have lost untold hours of sleep worrying about the future and how we will pay for it all. But, I have also experienced the wonder of a life returning from the brink, the newness of an old love, the kindness of strangers, and the incredible goodness in most people.

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CAMP BRUCE MCCOY

This spring marks the 20th anniversary for BIAV's Camp Bruce McCoy. This residential camp, held in Chesapeake, offers adult survivors an opportunity to participate in a variety of typical "camp" activities. There are two one week sessions (May 18 - 24 and May 25 - 31). This is also a wonderful opportunity for students in a wide range of educational programs (O.T., T.R., Nursing, pre-med, P. T. etc.) to get invaluable experience working with survivors and learn about brain injury. To get an application for camp or to find out more about staff positions, please call (804) 355-5748.

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Interviewer: A good amount of time has passed since your husband was in the hospital. What's life like for him now?

Mrs. Rawlins: My husband has lost his job and is on long-term disability. He cannot participate in the sports he once loved, cycling or skiing, they pose too high a risk for him. His stamina is much less than it used to be. He is on several medications and requires lots of rest. He has lost his right to drive a car due to TBI complications. Most of the things that once defined him are not options for him anymore. He has had to virtually retrain himself and remake his life over. He fights depression and tries not to become obsessed with these losses. We both struggle with how to arrange our lives to make them work.

Interviewer: You mentioned concerns about the future during one of our earlier conversations. Could you please explain?

Mrs. Rawlins: We have a diminished sense of security. We have found first hand that serious accidents can and do happen, and that brings with it an element of worry and apprehension in many situations that did not exist in our imaginations before. Brain injury is a rolling tumbleweed of trouble. First you think it's a physical injury that will just heal. Slowly you realize it's so much larger and more complicated than that. Changed personality, speech, balance, vision, thinking, memory, comprehension, can all become problems that persist. Just last week, ten months after his injury, my husband suffered his first seizure while working out at the gym. It totally took us by surprise and forced us to confront the fact that new challenges would arise from this one injury, possibly for years to come.

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Interviewer: What about your family has helped you adjust?

Mrs. Rawlins: We are not a family who hides their feelings and that has helped us. We express ourselves to each other and can help each other as we go along. We seem to take turns picking each other up with a hug or a pep talk. We all try to rally around Hugh so he does not get depressed.

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Interviewer: Can you summarize for us now and tell us how your lives have been affected?

Mrs. Rawlins: How have our lives been affected? In all ways. It affects personal dynamics, friendships, and feelings of self-esteem due to forced dependency. It affects jobs, income levels, and expenses. It introduces possible legal action and the stress related to that. It requires constant treatment, medication and the

management of insurance policies. It dumps stress by the truckload on the caretaker and the inflicted. It requires time and patience, and who has that when you have all of the above?

Interviewer: You sound like someone who's learned a lot from a difficult experience. Have you thought about what you'd tell other families going through the same thing?

Mrs. Rawlins: Our old lives clearly do not work now. Long hours in a demanding job are not an option for my husband anymore. Perhaps the true essence of what we were meant to do will now reveal itself to us. Rather than tying ourselves to past routines, we can explore new possibilities. We are both looking in new directions. We continue to rely on the medical community that embraced us and our family and friends. Without a network of people to help, listen, and pull us out from under the blanket of despair every now and then, we would not have done this well.

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Interviewer: Have you found it hard at times to have hope?

Mrs. Rawlins: We keep facing new problems but we are able to work through them and still have good times. It all boils down to persistence and the determination to keep saying, "I can do anything for one hour, one day, one week, one month, one year..." It is hard, it's very hard, but it's doable. We just have to believe there are better days to come and hope, that maybe, they will be the best days of all.

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Interviewer: Thank you so much for sharing your experiences. I'm hopeful that what you've said will make it easier for others.

This interview was conducted by Jeff Kreutzer and Laura Taylor from the VCU TBI Model System Family Support Research Program. For more information about the program, please contact Laura at 804 828-3703, toll free (866) 296-6904, or email: taylorla@vcu.edu.



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