

Look Straight Ahead

"I think I had a PTSD moment ... I was in the car Wednesday and was suddenly physically in the ER the night of Bonnie's aneurysm rupture. I was aware of the temperature in the room. I could hear the sounds...I noticed the blanket that was on Bonnie...and the respirator. I was having a flashback to the first moments of seeing Bonnie in that environment. I was more aware of the room than of Bonnie."

"... What I'm doing is not humanly possible. Anyone in the business would put Bonnie in a home. I'm not willing to do that...I guess it's going to be at my own expense. I gave her CPR that day in the gym. That's why she's alive. She never would have made it out of that gym..." Thinking about myself is almost like letting go of Bonnie...I am tearful when I have the opportunity to do something for me..." "It's our 20th anniversary...I was remembering who Bonnie was..." ...Knowledge is my sanity. It helps me to control what I can..." "My exhaustion is opening all of this up...the dam is breaking...it's bulging, and drips of water are coming out. The exhaustion is putting holes in my mental stamina...how much longer can I do this before I am hospitalized myself"? ...Even as I ask the question, I am gratefully connected to the loving support of my mother's presence in the echo of her message: 'always look straight ahead.'"

Maureen, it has been very much my privilege to witness your experience these past few years, not only as you continue to face the peaks and often valleys situated in Bonnie's journey, but as you negotiate the consequent detours popping up along your own path, as Bonnie's partner in life – a path that has been lined with more questions than answers, more uncertainty than clarity, more aloneness than connection.

Reflecting on earlier conversations in our time together, I am reminded of what was demanded from you as early as within minutes of Bonnie's brain aneurysm. Consumed by fear, you were able to harness a presence of mind that allowed you to stay present for her. Your ability to “freeze” chaos in the moment, allowing you to assess immediate needs, enabled you to administer life saving measures, not quite knowing what has happened. In the days to follow, your ability to prioritize and give voice to her further needs, not only to family and friends, but to hospital staff, ensured space for Bonnie to find and begin her arduous journey to a place from where she can, within her limitations, continue to participate in life.

In the time since, you have come to understand in an entirely new way that “knowledge” is your ally. With this understanding, you have committed yourself to learning the language of Bonnie's newly acquired landscape. You have learned to ask the questions. You have learned how to question the answers. You have identified the role you want to play in your partner's life and have made your mark as an unquestionably capable supportive “team” member. Your openness to acquiring, and commitment to developing, a working knowledge of many of the skills required in Bonnie's care has allowed for a certain comfort in an otherwise frightening, uncertain, exhausting and overwhelming experience. Rather than being left on the outside looking in, you are very much a part of the inner circle of care. This will and ability to continue to cultivate knowledge and understanding has positioned you well, not only among those treating Bonnie medically but among her family. Your voice has become a voice listened to, resulting in your

successfully securing your right to be privy to, and make decisions regarding, Bonnie's treatment plan, decisions that have met with remarkable results, decisions allowing Bonnie to move through her experience with a certain dignity that might not have otherwise been available to her. This dedication to learning how “to be” with and for her continues to earn you the respect of all involved in her progress.

Along the way, you have had to contend with personal change and loss, at almost every turn, involving consummate levels of courage and/or letting go: relationally, socially, internally:

Relationally, while Bonnie's progress has exceeded beyond anyone's expectations, you have had to embrace the reality that, in spite of the gifts she continues to bring, the love of your life is no longer able “to be” in a relationship with you as she once was. As you continue to do battle with the ambiguous nature of the many resulting thoughts and feelings inherent in such a loss, you are regularly having to redefine your relationship in general, and your role in particular – adjusting over and over to the “new normal.” Though your body and your mind are often tired and from time to time struggle with “conflicted feelings,” you have allowed your heart space to be easy ...and can go there to rest.

Socially, because you have experienced few as truly understanding the choices you have made, you have been sensing a growing divide between you and many in your social circle – not due to their lack of caring but more perhaps to their difficulty in knowing “how” to convey their sense of caring in a way that feels supportive to you. Rather than closing doors, however, you have allowed yourself to become open to ways by which you can create a shift in your social approach, giving yourself permission to prioritize your needs. Preferring to be in the company of those who understand and who are accepting of your journey, those who “get it,” you have been willing to consider what it might mean to “teach” others how *to be* with you and Bonnie in a way that feels comfortable to you, rather than continue to expend precious energy in your attempts to assuage their discomfort as they struggle with what to say or what to do ...teaching them how to be present in ways that feel respectfully supportive so that the door may remain open.

Internally, you have been recognizing a shifting and stretching going on inside. Increased interaction with hospital staff during Bonnie's medical visits and hospitalizations has provided you with the experience of feeling part of a “team.” Fostering a “knowledge is power” paradigm, your recent attendance at a brain injury conference afforded you the opportunity to experience yourself in the company of people of similar experience. Listening to the speakers provided you with new thoughts to consider. Interacting with conference attendees had the effect of minimizing your sense of aloneness. Both offered an appreciated sense of validation. Your willingness to explore beyond your immediate experience has not only had the effect of shifting your dance with isolation, but has opened you up to the possibility of further change ... this time, of a more adventurous, rather than traumatic, nature as you consider ways by which you might begin to further tap into connecting opportunities. And of no small outcome in all of this is an emerging energy on your part, dedicated to beginning the work of “building a life” for yourself. Not a life that doesn't include Bonnie, but rather, one that will support your ability to continue be with and for her in preferred ways. You have

discovered that in cultivating an appreciative audience you feel less alone. You are aware of a shift in mental and physical energy when you engage physical exercise. And you have been reconnected to the possibility of relaxation and enjoyment in social discourse. Three “giants” that, when implemented, strengthen your resolve to look beyond the face of unrelenting unpredictability, into the eyes of your mother's teaching “always look straight ahead.”

As I reflect on your story, Maureen, I am reminded of a Buddhist teaching I read quite some time ago, one informing us that if we're going to walk a path, we must first learn the skill of walking since there will be few places to sit. It took many more years of life experience for me to grasp what this meant. As witness to the unfolding of your story, for my part, there has been much more to learn, and, for all of it, I am truly grateful.

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