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1996: The Delicate Balance of Working Together

ACCOMMODATING THE MOUNTING CHANGES

Not even a full year into this disease and our daily routine was already changing.

Each morning, after a restless night of not sleeping well, Charles prepared for his day. He was still able to step over the high rim of the tub and shower on his own without incident. He continued to dress himself, with a few struggles. His fingers would defy him when he'd try to button his shirtsleeves. Though he was reluctant for me to do so, I began to take on that task. And then he'd get frustrated trying to knot his silk tie. As he lost the coordination to loop its ends around, I stepped in. At first that created a problem for me, as I didn't know how to tie a man's tie. And then once I learned, he was rarely happy with the off-kilter knot I made.

Before leaving the bedroom, Charles would down his new designer pills touted as having superantioxidants powerful enough to preserve brain health. He'd become a guinea pig because scientists hadn't—and still haven't—found a cure, or even an effective treatment for the diseases they hypothesized he might have. We hoped to discover, by trial and error, something that would stop the disease's relentless progression.

Once Charles was dressed and ready, the stairs were his next obstacle. With our bedroom on the second floor and our house sitting on a hill, Charles had to maneuver down more than two flights of stairs. He

would carefully lower each foot to reach the next step, his deteriorating depth perception compromising his navigating ability. To provide additional support for Charles, we'd recently installed handrails on the elegant front stairway inside our hundred-year-old Victorian home.

Charles still drove the twenty miles or so to the small corporate headquarters where he worked, but I insisted he take the old silver Dodge Aries I had bought from my grandmother's estate after she died in 1989. The new champagne-colored Ford Taurus needed better care than he could usually provide, his carelessness with food and drinks in the car now worsened by his diminished control over his body.

At work, Charles's difficulties persisted. His typical duties as vice president of manufacturing included attending meetings, conducting phone conversations, reading reports, working on projects, and developing strategic plans. Each day's tasks invariably required reading. His eyes struggled to track across the page, making it difficult to get from line to line. At times this was compounded by double vision—his eyes were not working well together. And because he also had difficulty seeing and recognizing objects, he moved his most-used file folders into an open holder on the wide windowsill next to his desk.

Soon his beautiful, distinctive writing style began to deteriorate into squiggly lines he could barely control. This made him more dependent on the computer, even though he had never learned to type with more than one finger.

When he arrived home, he would still chop and grill and stir, fixing a wonderfully fresh meal we'd eat in our newly renovated kitchen. I've never been a good cook. In fact, I hate to cook, so Charles had taken on this task for us. Watching him now, I wondered, *How much longer will he be able to wield a knife and handle the utensils required for cooking? And what will we do if I have to start doing the cooking?* Those thoughts, however, took a backseat to my worry about how Charles would feel when he lost this ability.

On a typical evening, we would simply watch the news on a major TV network and then one of our favorite sitcoms, such as *Mad About You* or *Frasier*. Finally, we would prepare for an early bedtime.

During our evening conversation, Charles often complained, "I just feel spacey all day. I don't feel like myself."

“Maybe it’s those experimental drugs you’re taking,” I’d respond, not really knowing if the culprit was the drugs or the advancing disease. And I could tell that even with the new sleeping pills and antidepressants he was taking, his bouts of insomnia and depression were growing more frequent.

“My feet don’t feel like my own,” Charles would also say. “I look at them, and cognitively, I know they’re mine, but they don’t feel like mine.”

When we had asked Dr. Ravin, his neurologist, about this strangest symptom yet, she had replied, “When your limbs feel detached from your body, it’s called alien limb phenomenon.”

“Are you feeling that funny sensation tonight?” I asked him.

“Yes,” he answered, “and it’s such a weird feeling.”

How could all of these losses have happened within just the first year that this disease had become evident? Somehow, Charles and I resiliently adjusted our daily tasks to accommodate his internal thief.

Caregiving Affirmation:

You can handle losses if you take them as they come.

I BLEW IT

I didn’t realize how sensitive Charles was about whether or not to tell others about his condition until the day I blew it.

When his first symptoms started to develop, he mentioned that he didn’t want to tell anyone—not his friends, not his work colleagues, and not even our families. “I’m afraid they’ll fire me if they find out,” he said, not wanting to lose the job he loved.

“What about talking to Carolyn?” I asked, referring to my sister, who is trained in speech therapy. “Don’t you think she would be helpful now?”

Charles agreed that we could confide in her. When she had lived in Arizona, Carolyn had worked with people who had Parkinson’s disease. Midway through her wedding reception, about ten of her patients sat in chairs placed in a semicircle. Carolyn sat in the center, her puffy white wedding gown flowing to the floor. We all looked on with astonishment

as she led them in songs like “Hey, Look Me Over.” Though many of the patients had difficulty speaking, all could sing.

I thought that Carolyn’s experience with neurological diseases might help Charles at this point, as his speech had already started to slow. Charles agreed, giving the okay to tell her. But though Carolyn encouraged him to tell others, he continued to refuse. Charles wanted to keep his condition very private. He thought he could hide it.

I, on the other hand, had difficulty keeping this tragedy to myself. My way of coping at this stage was to talk about it with family and dear friends; I had found relief and support by sharing the news with a few of those people closest to me. And I didn’t feel that his fears about getting fired were legitimate. Surely the executive team at Web Industries would not take such extreme measures, and would be supportive. I couldn’t convince Charles of this, however; his fear was very real.

I soon found that I couldn’t keep it in any longer—I had to tell others about what Charles and I were going through.

I remember the day I told my team at work. At one of our weekly staff meetings, we sat at a table over lunch at a wonderful nearby cafeteria. I was eating the half-portion of the pasta of the day that I usually ordered, and my favorite low-fat chocolate yogurt cake.

Charles and I had been immersed in our research on PSP and CBDG, two of the possible diagnoses. That was how we had learned that both conditions had dismal prognoses. The harsh reality—that Charles actually had a devastating disease—had just become real to me. The fact that he would die young shot straight through my heart.

While I was conducting the staff meeting, my emotions suddenly welled up and overwhelmed me. I needed to tell my team members *something*; I couldn’t just continue to talk about the items on our agenda. Giving in to tears, I looked around the table and said, “I need to tell you something. Charles has a neurological disease . . . and the prognosis is not good. It will probably take his life early—maybe in five to ten years.”

Everyone expressed sympathy and asked questions to clarify what we knew about the disease, but they really didn’t know what to say to this shocking news. As I thought back on it afterward, I wondered if I should have told them. All I knew at the time was that I simply couldn’t

bear the sadness by myself any longer.

When I told Charles that I had talked to my staff about his illness, he unleashed an anger I had rarely witnessed in him. I don't ever remember his being disappointed with me to the extent that he was over this issue. Such a strong reaction was out of character for him. I could count on one hand the number of fights we had had in our long marriage. I felt hurt; he felt betrayed.

"Who else have you told?" he demanded. I confessed that I had also talked to my close friend Jean and to my family. I felt pangs of guilt that I had broken the trust between us. I worked hard to understand the diverse ways Charles and I handled this issue. I obtained tremendous insight when I participated in the Myers-Briggs inventory training at work.

The Myers-Briggs Type Indicator (MBTI) explores people's preferences on four scales. The "energizing" scale looks at where we like to focus our attention or where we get our energy from, whether outside of us (which is labeled as *extrovert*) or within us (*introvert*). This is a bit different than the way many of us define *extrovert* and *introvert*. The "perceiving" scale shows the way we like to look at things, either focusing on the concrete or on what might be. The "deciding" scale measures whether we typically make our decisions either in a logical way or more from our values. And the "living" scale shows how we deal with the world around us—living a planned and organized life, or living more spontaneously.

I learned when I took the MBTI that I was predominantly extroverted on the "energizing" scale. When he had taken the MBTI a number of years earlier during his executive MBA program, Charles had scored as an introvert. We were opposites when it came to where we got our energy. I got my energy from others; Charles got his from within.

I would have initially guessed that Charles was an extrovert, because he was such a people person. He engaged in intense conversations with others. But as I think more deeply about those conversations, he was always the one asking the questions, finding out a lot about others but revealing little about himself. For Charles, who grew up in a fundamentalist, conservative Christian household, family matters always stayed at home.

During the MBTI program at my job, the company trainer led us in

a variety of exercises designed to help participants see the differences on each of the MBTI scales. She also promoted the positive nature of working with this diversity.

The trainer described a scene from the movie *Ordinary People* to help explain the differences between introverts and extroverts. In the movie, Calvin and Beth were Conrad's parents. Conrad had tried to commit suicide after the tragic sailing death of his older brother, and then had been taken to a mental hospital. Recently released, he was back in school but still receiving counseling from a psychiatrist.

When Beth and Calvin were at a birthday party, Beth overheard Calvin telling one of their good friends that Conrad was doing better and was in therapy. On the way home from the party, Beth boiled silently. She finally accused Calvin of going too far in telling all to their friend. She repeated a number of times that this was a "private matter"—just between them—and not to be shared outside of the home.

The trainer described Beth as being an introvert who needed privacy, and Calvin as being an extrovert who found energy, and therefore comfort, in sharing his difficulties with others. I finally understood the tension between Charles and me. As an extrovert, I needed to talk to others to survive. But as an introvert, Charles needed to deal with his issues quietly, within himself.

With this newfound awareness, Charles and I could finally understand our differences.

No matter how wise we are, working through differences like these will always require extra effort. I had to handle not only my sadness at Charles's disease, but also the impact of the different ways that we each dealt with it. And not just with this incident, but with many others throughout the course of the disease. I've learned that couples need to understand these differences in order to discover the delicate balance of working together, which flows out of respect for each other. Through that respect, couples can find the grace and forgiveness they need to overcome conflicts.