

## **CHAPTER 9**

### **Sharing the Same Shadow: Challenges of Parenting a Special Needs Child**

Looking back on my life with Kim brings me great joy and great pride. He has grown and matured in ways I could never have imagined. People so often focus on his unique abilities to recall even the smallest of facts, and indeed he has enormous mental capacity. But in my interactions with him I am so frequently reminded that the only part of him that is larger than his brain is his heart. I love him completely.

It has been a long, exciting, often frustrating, wonderful journey, and I feel truly blessed. Kim has made me feel more strongly about how valuable life is. We've struggled at times, but at the end of the day I feel that our struggles have made us stronger, brought us closer, and allowed us to help others see different parts of life and meet different kinds of people. Kim has turned my life around 180 degrees. He's a very literal person, but also has a unique brand of intellectual curiosity that causes him to think about

some incredible things. He makes me ask a lot of questions I would never otherwise have asked.

Recently, Kim has been talking to me about quantum mechanics. He tells me he wants to get quantum mechanics into our lives so that we can go to the fifth or sixth dimension to get away from the limited mentality of the present human race. He has also told NASA to hurry along their work to get us nearer to these new dimensions. I don't exactly understand what he's talking about – I guess my brain is stuck in the limited mentality of the present human race – but I'm sure he's on to something!

Several years ago, a psychiatrist asked Kim about our "unique symbiotic relationship." Kim's response rendered me speechless: "Dad and I share the same shadow." When I heard this, my heart beat double time. Doctors say he can't reason; I think his statement came from his heart, not from his brain.

People who know us well and even most people who just meet us briefly have commented on our unusually interconnected relationship. *Rain Man* screenwriter Barry Morrow told an interviewer for a recent documentary on Kim,

When I think about Kim's future, I can't help but think about what we lose when we lose Fran. What we lose is the interpreter. Fran is the code talker because Kim speaks in elliptical ways and Fran knows all the pieces of the puzzle that Kim isn't sharing because he's past it already. Fran walks behind like the elephant, sweeping up, while Kim marches on forward with all this going on, and if we don't have Fran

there who's going to tell us what we're missing?  
(Hofer, P. & Rockenhaus, F., 2006)

Barry's words really captured the essence of our relationship. Not only are we emotionally close, but we have developed our own way of communicating and understanding one another. Even though Kim knows the answer to just about any question you can throw at him, he doesn't always reply in a clear, understandable way. He often speaks entirely in predicates, leaving the subjects quietly resting in his thoughts. I try to get him to tell me the subjects so that we can complete the circle. Once he does so, his comments become clear and meaningful.

Over the years, I have become able to follow Kim's erratic trains of thought. He tends to fixate on the memories of certain experiences we have had or information he's read that has been particularly noteworthy to him, either because he found it amusing or it was a highly covered news story. Any number of statements or questions can trigger an association with these memories.

Once the association has been made, Kim is off. Without offering a clue or making any segue, he will



begin to quote a person or a headline, or sing a song that he relates to whatever he has just heard. Because he frequently returns to the same memories, I can often decipher what he's making reference to and how he made that connection. I used to have to ask him to explain some of his erratic topic shifts, but now, before I can even ask, he will volunteer, "You know how I got that, Dad?" Usually I do, and when I don't he explains it to me in a way that probably no one but I could understand.

Through spending so much time with Kim and through his talking to me about much of what he learns, I am perhaps one of the world's most knowledgeable non-savants! Occasionally, I find his incessant questions and explanations of news items and other subjects a bit frustrating, but usually patience prevails.

When Kim's talking – which is most of the time – it's almost impossible for me to concentrate on activities that require focus. He speaks very loudly and quickly, and gets very animated when he talks about things that interest him, making it difficult for me to concentrate on anything or be productive. The only time I can reliably expect to be able to read, write checks, prepare correspondence or make phone calls without interruption is when Kim is asleep, so I often end up having to do most of these tasks between midnight and 2:00 a.m., at which time he's snoring like a locomotive.

Sometimes I wonder just how Kim truly feels about our relationship. He does not usually talk about his feelings and has difficulty verbalizing emotions,

yet every once in a while he will say something that hits upon the true nature of his feelings about the pair of us. Of course the most poignant comment was probably his reference to us sharing the same shadow, but another, more recent example also stands out in my mind.

It had snowed a great deal on one particular night, with over six inches covering our patio. Kim worries about the weather... *really* worries about it! Being preoccupied with the snow, he had been walking up and down the stairs, obsessively checking on the status of the weather and monitoring accumulation totals throughout the night. Just as it was time to get up, Kim came into my bedroom, sat down on my arm, cupped his large hands around my face, peered into my eyes from about six inches away and whispered, "Dad, being with you is so important to me. You are the father of my heart." I don't know what made him say that, but I know that the words came from the bottom of his heart.

As most parents of children with disabilities will tell you: "We have a 30/10 schedule – 30 hours every day and 10 days per week." It is so true! Having a child with a disability means sometimes short changing others – and oneself. The special needs of the child must come first, which can be difficult for others to understand and accept.



Sometimes people become resentful, even angry. Creating this balance between the challenges of a child with disabilities and the needs of other family members is indeed monumental. It isn't always possible for a parent to be successful on both counts. Perhaps this is where the phrase, "fair is not always equal" needs to be considered.

Over the years I have become more sensitive to this and try not to give other people short shrift, but try as I may, there is a reality to our circumstances that other people need to understand, and which I try to explain. I hope that others will try to understand the difficult position of the caregiver. If people could walk around in the shoes of parents of children with disabilities for a while, I am sure they'd be a lot more patient!

