

CHAPTER ONE

Patience is Not Enough

It must be in the details

After a month, I now know enough about Helen to realize that she needs to tell me her stories at length. So I don't interrupt her anymore. I let her talk. The content of her life experiences are not as important to Helen as the littlest detail. There is something in those details that holds a key for Helen. Learning about her through her stories is like reading a mystery novel. Layer after layer of nuance and thread after thread of subplot is woven together and leads the listener deeper into Helen's world of loneliness and despair.

In spite of an ostensibly successful career and marriage, Helen sought me out for psychotherapy because she feels empty and disconnected from life. Perhaps a mid-life crisis? She is forty something, with shoulder length blonde hair and watery gray-blue eyes. She obviously appreciates her tall stature and slender body, since she dresses in stylish professional attire. Helen is attractive even in her forties. When Helen walks into the room, she is noticed. She has a powerful presence so it is a mystery to me that she feels so depressed and unfulfilled.

Others describe Helen as an assertive, articulate, and talented professional. And there is no doubt she is a caring and devoted wife and mother. But as Helen weaves her stories of life with her husband and children, there is something she is trying to tell me but can't quite put her finger on. She often refers to it as "the sliver

in my mind,” as if releasing the sliver will free her of the confusion and suffering she feels.

I recognize that Helen’s home life is odd. Her husband, Grant, seems a bit eccentric and immature, but I can’t quite put my finger on the problem either. Like Helen I am worrying a sliver in my own mind also. I want to help her but so far I don’t know how, except to listen. I want to understand what stands in the way of a meaningful life for Helen. It must be in the details.

Lying on the Floor

The room was pitch black so I knew it was still the middle of the night. I could hear the pulse in my ears and feel the clammy, tingly feeling as the blood rushed back into my neck and chest and fingers. I don’t know how long I lay unconscious on the bedroom floor but it could not have been very long since my pajamas were warm with urine when I lost control of my bladder. I must have fainted when I tried to make that last move to reach the hallway to the bathroom.

I lay quietly for a moment as the consciousness of what had happened spread through me. It was another of those many moments that makes no sense in my life. I had awakened in the night with that familiar sensation that I needed to urinate. Grant was sound asleep next to me. I rolled over on my side to get out of bed when I felt an intense bolt of pain rip through my lower back. I moaned and fell back into bed. My husband did not stir.

Wide awake now and breathless, I tried again to get out of bed but did so gingerly because I knew this feeling. I had a pinched nerve in my lower back (from an old injury and it would occasionally flare up unexpectedly). It would be a long trip to the bathroom. Inch by painful inch I moved my half bent body to the edge of the bed and fell to the floor, gasping for

breath when the pain grabbed me by surprise. I was able to hang onto the edge of the bed and creep along the side, but could not stand up. Each time I tried the pain was so intense I almost fainted. Periodically I would stop and take a breather, which would cause more pain. Holding my breath seemed the only way to get to the bathroom. My husband slept on.

Maneuvering the corner of the bed was another harrowing experience. I took a risk and decided to turn the corner, even though this took some sophisticated movements. I tried to stand and turn at the same time, but I lost consciousness for a moment. Fortunately I came to in enough time to grab the footboard and keep from falling. I screamed in pain though because this risk was too much. Not one sound came from my slumbering husband.

I was gaining confidence as I inched along the foot of the bed to the doorway leading to the hall and the bathroom. I was at a crossroads . . . to stand or to crawl the rest of the way since there was no more bed to hang onto. I even felt an odd sense of accomplishment that I had made it this far and that I had not disturbed my husband's sleep. Feeling brave I stood up, but this time I did not feel the pain or the impact of hitting the floor. Losing consciousness spared me this suffering, but not the emotional abuse that was to follow.

I felt the warmth of my wet pajamas so I knew I was alive, but I was humbled. I knew I could not get any further without help. I called to my sleeping husband, but before I could finish saying his name I felt the pain again. Even that much activity pulled the muscles that squeezed the vertebrae. So I tried another tactic. I lowered my voice and spoke from the back of my throat, hoping that he would hear me, wake up, and help. "Grant." There was no response, so I tried again, "Grant, I need help."

This time he heard me. What a relief! But he responded in his characteristic way that makes no sense at all at times like this. He said, "What do you want?"

I have lived with this man for two decades and have become accustomed to this unfeeling style, so did not skip a beat in responding to him. He always needs my help in understanding these simple things. Still speaking slowly so as not to create pain, I said, “Grant, I need your help. I cannot get up. I want you to get up out of bed and come help me stand up so that I can get to the bathroom.”

“Now?!” he said, with great incredulity.

“Yes, Grant. I need you to get up and help me. I cannot move. I am in great pain. I fell to the floor because I have a pinched nerve in my back. You must help me get up.”

“Oh,” he said. “I was wondering what you were doing on the floor.”

Grant had been awake the entire time Helen was making her painful journey around the bed and across their bedroom. He observed her with that detached perspective of the man with Asperger Syndrome (or AS), unable to “connect the dots so to speak.” He was not in pain so he could not relate to Helen’s. It was night and time for sleeping so he focused on that, not understanding how to transition to the new situation her odd behavior posed. Even when he got out of bed to help Helen, she had to instruct him how to lift her to avoid the pain. She had to ask him to get her clean pajamas. She had to ask him to wait for her in the bathroom. She had to ask him to get towels to clean the carpet. She had to ask him to help her back to bed and to walk her to her side of the bed. Even the next morning, she had to remind him that she needed help and to call the chiropractor for an emergency visit. He could not problem solve any of this. Instead of being concerned for Helen’s health and wellbeing, he worried about being late for work when she asked him to drive her to the doctor.

Yes, the details reveal the nature of Helen's life with an Asperger husband, but how do I help her? Asperger Syndrome is incurable. Is there another way?

Let Me Guide You Through the Looking Glass

If you live with an Asperger husband or another family member, Helen's story does not seem unusual. It is part of your every day life. If you have these experiences but are not yet sure if your spouse has Asperger Syndrome, you may be startled by the uncanny similarity of your life and Helen's. Some of the facts may change from story to story and couple to couple and family to family, but what is constant are the symptoms of Asperger Syndrome that create chaos, fatigue, insanity, and heartbreak in your life.

In this book I will share stories from my life too because I also have family members with Asperger Syndrome. Although some psychologists know a little about AS in children, they know next to nothing about what happens when these children grow up and marry. They don't know the mind-numbing story that is hidden in the details. On the other hand, instead of a clinical overview of the disorder, I write stories from the heart, the heart of a woman who lived through a lifetime of extreme pain and loneliness. I know too well how Helen feels. The loneliness is perhaps the greatest heartache I lived with. It is hard enough to have an abusive, emotionally unavailable man to live with, but the problem is compounded by having no other person in your life that understands or believes what you are going through. I want those of you who are living this life to know that there is at least one other person who knows. And I want to help you get the life you deserve.

Writing this book is doing that for me.

You may not relate to all of my stories or Helen's. Not everyone with Asperger Syndrome is the same. Personality and environmental influences affect how all of us will mature. And because AS is a developmental disorder and actually a constellation of many traits, not all of those afflicted with Asperger have the same problems. For example, Helen's husband is clumsy, has night blindness, can't recognize faces easily, has a volatile temper, is obsessive about work, and is addicted to television watching. But another with Asperger Syndrome may be artistic, shy, slovenly, anxious, fearful of confrontation, and disorganized. But what all Asperger people seem to have in common is the effect that they have on their loved ones. Because they are not able to empathize, they leave us feeling alone and crazy. The relationship seems more like that of caretaker to a disabled person.

Through these stories of real people and real lives I hope to educate you about AS and how to cope with it. It is incurable. You, the caretaker of these individuals will have to do all of the work in the relationship. However, the more you learn about the syndrome, the easier it will become to live your life and disconnect from blame and guilt and the crazy adaptations you have made in order to live with these people.

Looking at the story in this chapter, do you see the craziness? Why didn't Helen ask for help right away when she felt the first bolt of pain? Why did she assume her husband was asleep, after years of living with this man and knowing better at another level? Why was she proud of taking care of herself? Why did she have to explain the obvious to a grown man? Where is the caring for the caretaker?

I will answer these questions for you and go beyond the usual textbooks on Asperger Syndrome.

Living with an Asperger mate is like being permanently on LSD. You think you have traveled through the Looking Glass into another dimension and like Alice you have no reference points for relating to the situation. I want to give you those reference points, so that you can navigate this world. And I want you to go beyond mere survival in the Asperger Dimension. Once you know the territory, you can choose to stay or leave . . . at will. That is important. That is freedom.

At this point in the story and your own personal self-discovery, you may not even know what I mean by reference points or freedom. The bottom line is that if you are living with an Asperger mate or child or parent, you feel trapped. You might even feel as if you are in prison. In this book I will show you how to gain the freedom to take back your life. Patience is not enough anymore. You must be brave and you must take action if you are to get out of the war zone and create the life you deserve.

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