CHAPTER ONE

Patience Is Not Enough

The story of Helen and Grant begins in this chapter, but it is by no means the beginning of Helen's story. It is only after years of living with an undiagnosed Asperger mate that Helen finally comes to realize that patience is not enough. In this chapter you will learn that you are not alone if you also live with this type of family configuration. For your recovery, it is important to know that you are not alone.

Mind Blindness and Safety

Patience is a virtue, I've been told, but dealing with the mind blindness of an Asperger mate requires more than patience. Mind blindness is the phenomenon whereby Aspies have no idea of what is going on in the mind or life of another person. They cannot put themselves in the other's shoes and anticipate the next step in the conversation or the relationship.

Faced with this, coupled with the Aspie's rigid thinking and anxiety about anything out of the ordinary, many neurotypical (NT) spouses find it necessary to look for methods of coping, even though it is not always productive. NTs make excuses for their spouse's social inadequacies, carry more and more of the load for the relationship or begin to lose their sense of self in the oppression of their Aspie partner's one-sided thinking. Some NT spouses even begin to fear for their personal safety, not so much because of physical violence, but because their partner seems clueless about the safety needs of family members, including children, parents and themselves.

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 any more. I let her talk. The content of her life experiences is not as important to Helen as the littlest detail. There is something in the details that holds a key for her. Learning about her through her stories is like reading a mystery novel. Layer after layer of nuance, and thread after thread of subplot, are woven together and lead 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 blond hair and watery gray-blue eyes. She appreciates her tall stature and slender body, dressing in stylish professional attire. Helen is attractive. When she walks into the room, she is noticed. She has a powerful presence, so at least on the surface, it is a mystery 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 a bit odd. Her husband, Grant, seems eccentric and immature, but I can't quite identify the problem either. Like Helen, I am worrying a sliver in my own mind. 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.

CHAPTER ONE

Lying on the Floor

Helen tells me a story.

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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 of the blood rushing into my neck, chest and fingers. I don't know how long I lay unconscious on the bedroom floor, but it could not have been long since my pajamas were still warm with urine from when I lost control of my bladder. I must have fainted when I tried to make that last move to reach the hallway to get to the bathroom.

I lay quietly for a moment, as the consciousness of what had happened started to spread through me. It was another of those many moments that make 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 it gingerly because I recognized what I was feeling. I had a pinched nerve in my lower back (it stems from an old injury and occasionally flares 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 as 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 to get up, the pain became so intense that 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. In the meantime, my husband slept on.

Maneuvering around the corner of the bed was another harrowing experience. I took a risk and decided to turn the corner, even though this required 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 time to grab the footboard and keep from falling. I screamed in pain. Not one sound came from my slumbering husband.*

I was gaining some confidence as I inched along the foot of the bed toward 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 felt an odd sense of accomplishment that I had made it this far and 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. A loss of 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 farther without help. I called to my sleeping husband, but before I could finish saying his name I felt the pain again. Even that little 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 me. "Grant." There was no response, so I tried again, "Grant, I need help."

This time he did hear me. What a relief! But he responded in his characteristic way that makes no sense at times like this. "What do you want?" he asked.

I have lived with this man for two decades and have become accustomed to his unfeeling style, so I did not skip a beat in responding. He always needs my help in understanding even very 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 asked, with 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."

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Grant had been awake the entire time Helen was making her painful journey around the bed and across their bedroom. He observed her with the detached perspective of the man with Asperger Syndrome (AS), unable to "connect the dots," so to speak. He was not in pain, so he could not relate to Helen's pain. It was night and time for sleeping, so he focused on that, failing to understand how to transition to the new situation his wife's 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. Even the next morning, she had to remind him that she needed help and ask him 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 well-being, he worried about being late for work when she asked him to drive her to her appointment.

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

Let Me Guide You Through the Looking Glass

If you live with an Asperger's husband or another family member, I'm sure Helen's story does not seem unusual, even if the details are different. It is part of your everyday life. If you have these experiences but are not 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, couple to couple and family to family, but what is constant are the symptoms of Asperger Syndrome that create chaos, fatigue, insanity – and sometimes heartbreak – in your life.

In this book I will share stories from my life too, because I also have family members with AS. Although some psychologists know a little about AS in children, they know very little about what happens when these children grow up and marry. They don't know the often mind-numbing story that is hidden in the details. 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 live with someone who is emotionally unavailable, the problem is compounded by having no other person in your life who understands or believes you when you tell them 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 because it is something I have a passion for and have wanted to do for a long time.

You may not relate to all of my stories or Helen's. Not everyone with AS is the same. Personality and environmental influences affect how we mature. And because AS is a developmental disorder, and a constellation of many traits, not everybody who has Asperger's face the same challenges. 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 watching television. Another may be artistic, shy, slovenly, anxious, fearful of confrontation and disorganized. Most with AS have several sensory sensitivities, overreacting to loud sounds, intense lighting, strong fragrances or scratchy fabrics. Still others may be hyposensitive and not even notice the strong odors emanating from their unkempt room, or the chill that has crept up after sunset while they sat outside engrossed in a book. But what all those with Asperger's seem to have in common is the effect they have on their loved ones. Because they are not able to empathize, they often leave us feeling alone or crazy, and the relationship often evolves into that of a caretaker to a disabled person.

Through these stories of real people and real lives, I hope you will learn about AS and how to cope with it. You, the caretaker of a partner with AS, will have to do most 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 and go beyond the usual textbooks on AS, which tend to focus mostly on diagnosis and providing services to the child with AS, and offer little guidance or hope for the adult relationship.

Living with an Asperger's mate is like traveling through the Looking Glass in Lewis Carroll's classical tale. You think you have traveled 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's 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 personal self-discovery, you may not know what I mean by reference points or freedom. If you are living with an Asperger's mate, child or parent, you may feel trapped. At times, you might even feel as if you are in prison, or ready to go over the edge. Learn how to gain the freedom to take back your life. Patience is not enough. 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.

Lessons Learned

1. Trust your intuition. If the situation seems crazy, maybe it is.
2. Seek professional help from someone who knows about the interpersonal dynamics of Asperger Syndrome – not just the diagnosis, but what it is like to live with an Aspie.
3. Read this book over and over again and take it with you wherever you go, so that you will know that you are not alone.
4. Caretaking can be an expression of love, but if the result is a loss of your sense of self, it is no longer love. It becomes avoidance. Don't totally avoid your life in service to another.