A Journey Through Fire: ALS - Memoir of a Caregiver

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Life changed forever when the doctor diagnosed my husband with Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease. Extreme tragedy, dread, and grief surrounded us as the disease stalked him unmercifully. It finally defeated him with death after long months of torture. There were many challenges during our journey. We struggled to accept the inevitable, understand the disease and its consequences, and to find appropriate medical care and treatment. The mental, emotional, and heart-wrenching consequences of grief, despair, fear, helplessness, and then hopelessness were the greatest challenges of all. At the time of my husband's diagnosis, I had been a practicing R.N for forty-five years. I had cared for many people with serious or terminal illnesses, and suffering and death were not foreign to me. However, I knew little about ALS. I recalled from nursing school that it is a rather rare disease with no known cure. As I began the search for information, it became clear very quickly that this was no ordinary disease, but an exceedingly ruthless and deadly affliction. The care for someone with an illness such as this would be complicated. There was a great deal to learn, and I realized that I was not at all prepared. During my daily caregiving efforts, especially as the illness progressed, I had my nursing education, experience, and skills to assist me. I wondered how someone with no skills or medical background would ever be able to cope with the enormity of it all. I came to believe that if God showed me the way, lessons learned could equip me to help others who may take a similar journey. This is Bill's story, for the suffering belonged to him, as did the courage. The telling of it has not been easy. Many times since his death, I have sat down with the best intentions of putting it all together. However, feelings or images would take me back to some sorrowful time or event, and painful memories would not allow me to continue. The thoughts, feelings, perceptions, and conclusions found in the story are strictly my own; as witnessed from the vantage point of spouse, caregiver, and friend. The journal where I recorded those nineteen difficilt months provides the chronicle for the pages. Keeping a journal helped me to cope, stay focused on Bill's care, and retain some degree of sanity in the midst of the surrounding turmoil. I could pour out my anguish, my fears, and my frustrations onto its pages. The story details the physical, mental, emotional, and spiritual challenges involved in coping with an illness such as ALS. It contains a mixture of useful information about a mysterious, complicated disease; life lessons learned, and the fight to sustain life through medical care, perseverence, hope, courage, and faith. It is my sincere hope that this story will assist to light the way for someone who is caring for a person in a battle against this particular horrendous disease. My prayer is that something written on the pages will provide a measure of comfort and hope to anyone who may be struggling in the midst of a similar terrible trial. The story has been written in Bill's memory. Even though the telling of it has reawakened sadness, heartache, and grief, it has been cleansing for my soul. The reader will find that I sometimes faltered and stumbled along the way. I did not always make the best decisions. I put on my nurse's hat more often than I should have, and I wore it too long. The last months of my husband's life were especially trying, for I was dealing with my second bout of breast cancer when the ALS was having its worst effects on his mind and body. Even though the entire journey was difficult, the hardest were those last weeks and days when it was clear that he was going to die and leave me. I had to hold fast to my faith during those times, and when the darkest hours vanquished all assurance of hope...I held on mightily to God's enduring promises.

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