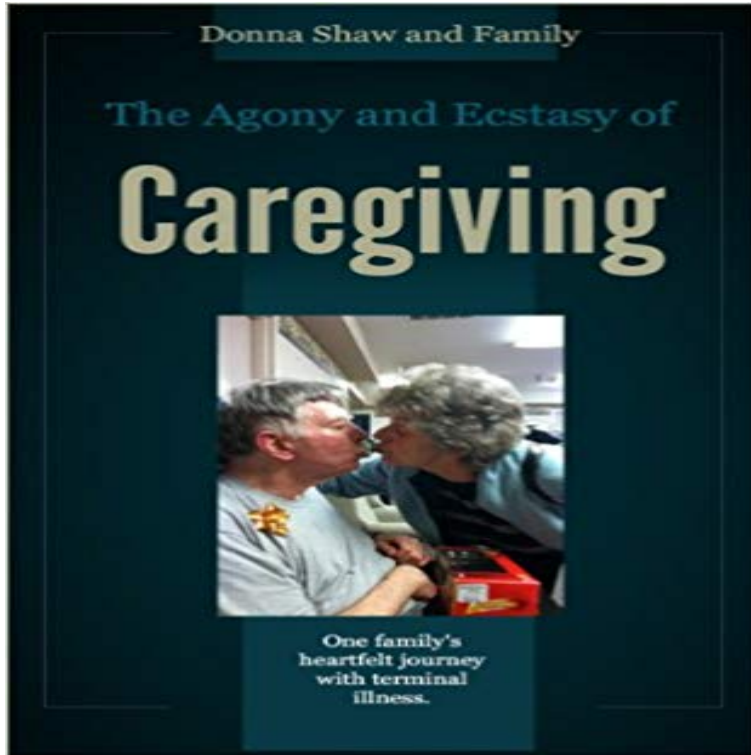


The Agony and Ecstasy of Caregiving: One familys heartfelt journey with terminal illness.



The doctor uttered the words, He has PSP, and those words would forever change our lives. What in the world is PSP? We left the doctors office in shock. We had waited years for a diagnosis, now what? My father who has now ended his journey with PSP is finally at peace. My mother tells me she misses the little things like the secret looks, the touch of his hand, a hug, and spending time together. In essence, she misses the connection. My father was a graduate of the University of Florida in Gainesville, with a Bachelor of Science in Electrical Engineering. He was kind and intelligent and he loved to travel, and he spent four years in the Navy during the Korean War, and he was first and foremost a family man. After the balance problems started, he began to do this little shuffle with his feet, we would ask him what this new little dance was and he would simply say, I dont know. The slow downward spiral had begun; we just didnt know it. Welcome to our story.. My mother, Donna Shaw, wrote this book to give people hope. She wrote the book over the last year, after my father passed away from PSP, Progressive Supranuclear Palsy in October of 2012. The book commemorates my fathers life as well as the experiences we all went through struggling to come to terms with terminal illness. Caregiving, whether or not you are caregiving for someone who has a terminal illness or not, is a very difficult process, a process in which one needs support. This journey you are about to embark on comes from the heart. Caregiving is often a thankless and challenging task, because you have to see the ones you love withering away. It is always hard when you have to give up hope, because sometimes hope is all you have. Diseases like PSP are not well known, and often misdiagnosed. The most frustrating part for us was the slow decline of everything my father held dear. In my mothers words: My husband is trying so hard to try and make things easier

for me, but it is a losing battle. Everyday we see a change. He is now losing the use of his right hand and arm and his speech is getting hard to understand. But I love him with all my heart, and will be there for him always, no matter what. We are grateful for every little moment we had. That is the blessing. I had time to tell my father I loved him, even if he had trouble telling me back. My parents were able to celebrate their 55th anniversary recently, although not in the way they expected. To put it in my mothers words: Happy 55th Anniversary to my husband Lyle, who has been in the care center for the past 6 months. We made it this far even though we are not doing what we intended to. I Love you, Donna. For now, it will have to be enough. The reason for this book is to make the public and medical society more aware of this devastating and little known disease called PSP or Progressive Supranuclear Palsy. This disease, which will be referred to as PSP, mimics some symptoms of Parkinsons and ALS or Lou Gehrigs disease. PSP has no known cause or cure and is extremely difficult to diagnose. Since this is such an unknown disease, those involved in the care of someone with PSP are in a very difficult position, just as much so as the person who has the disease. It is my hope that this story will not only help bring awareness to both the public and the medical field, but that it can be used as a tool to help find a cure as well as help those who are living through this life altering disease process. My family and I wrote this book to give people hope so that people would know that they are not alone. The journey we have been through has been difficult to say the least. It is our hope and our dream that this book brings awareness to this horrible, debilitating disease called PSP. We did not write this book just for those who suffer from PSP, we wrote it for anyone going through or watching their loved one die a slow and painful death. Welcome to our story. We wish you peace. Leslie Riopel

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