



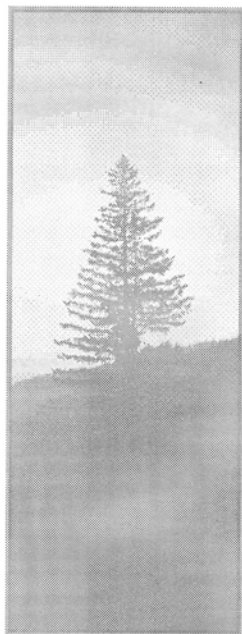
Share My Lonesome Valley

The Slow Grief
of Long-term Care

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of Long-Term Care



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Chapter I

The Lonesome Valley

As soon as they came into the room it was evident they were accustomed to being important. It was more than the clothes she wore, or the care she had been able to lavish on herself. There was an air about them that let you know they were more than just the people next door. She pushed his wheel chair up to a table and started gathering their coffee and rolls before the seminar began. Her husband could best be described as an imposing person. In spite of the effects of Alzheimer's, he still looked brilliant and powerful. When I introduced myself to them, she responded graciously and seemed genuinely appreciative. She walked me off to the side so her husband could not hear and said, "My husband started seven major companies. We were personal friends of President and Mrs. Reagan and have spent many nights in the White House. Now he has Alzheimer's disease and my heart just breaks for him."

I must admit that I missed hearing what I should have heard. I was so intrigued with the man, so curious about what companies he owned, and so taken with their frequent visits to the White House that I totally missed what she wanted me to hear. We talked about the businesses, and he had owned some very well-known large corporations. We talked about the Reagans and their close relationship. We talked about how ironic it was that both her husband and President Reagan had developed Alzheimer's disease. We talked about how horrible this disease is and how it robs brilliant people of everything they hold dear. We talked about how hard it is to see someone like her husband die by small degrees or millimeters at a time.

We covered every aspect of what was happening to her husband—BUT we never talked about HER.

What about her losses? What about her pain? What about her grief? As she was telling me about her husband, she was also crying out for someone to notice her pain. Finding a way to communicate the inner pain we feel when a mate has such a debilitating disease is difficult. How can you stand next to the wheel chair of a former titan of industry, who is in the advanced stages of Alzheimer's Disease, and talk about anything except his pain? Isn't that selfish? Won't it sound silly? How could your little pains even be mentioned in the same room, much less the same breath, as the losses sitting right in front of us?

But it is neither selfish nor is it silly. She may not have consciously known it but she was really saying, "*Look at what I have lost!* See how my life has been turned upside down. How can one go from luxury to nursemaid in such a short time? How do you live through losing your husband while his body is still alive? How do you survive the slow grief of thousands of small sorrows? How do you stand seeing this person, who was the strength of my life, shrivel into someone who can't drink his own coffee? Tell me how you do that and still smile for the world to see? Tell me how you do that and never let anyone hear a complaint? And yet, because his pain is so great, these issues and my pain are not important, not spoken, and not heard."

I could tell a thousand stories just like this one. I hear them all over the world. The diseases change, but the experiences of being dominated by the demands of care remain constant in each of the stories. The moment a loved one is diagnosed with such diseases as Alzheimer's, AIDS, Parkinson's, cancer, ALS, stroke, chronic depression or other emotional illnesses, and the list could go on, your name changes to caregiver. From that moment your life is dominated by that title.

Just as there are many kinds of long-term diseases, there are many different levels of caregiving. You may be a spouse doing

full-time care for a mate in your home. You may have already given care for several years, or you may be in those frightening early days of denying the diagnosis.

You may be a child giving care, either in your home or the home of your parent. In either case your role has changed completely. Your home has been lost for the duration of the care.

You may be caring for a loved one in a health care setting such as a hospital or nursing home. If so, you now spend your time walking halls and begging for more information.

Or, you may find yourself trying to give care from a distance. Your work demands that you live many miles from home and now your parents are in need. Your life is dominated by making phone calls to arrange for care, checking on conditions, or dreading to hear the phone ring for fear of the possible bad news. You spend every day off and vacation time making trips back home. Your work suffers, your home life suffers, and you still feel guilty for not doing more and being there more often. You face decisions about care that have no solid answers. The fact that you are not there in person providing care every day does not lessen the domination, nor the grief and pain.

It sounds impossible, but long-term care sneaks up on us. The need for care grows so gradually that we do not notice how much of our life is being controlled and dominated by the caregiving. Before we realize it, there is a hospital bed in the living room and oxygen tanks by the television. We are either giving care, or thinking about giving care, twenty-four hours a day. That has been called by authors Nancy Mace and Peter Rabins "The Thirty Six Hour Day." *The Thirty Six Hour Day*; Johns Hopkins Press, Baltimore, MD, 1991, Second Edition.

Families confronted with a sudden illness or a traumatic accident are much more likely to talk about what they are personally experiencing. They explain it in great detail at every opportunity. They are very aware of what they have lost. They are aware of how that loss is impacting their lives, and they tell the world.

Long-term care folks seem to just “function in the fire.” I have heard that if a frog is placed in a pan of cold water and put on the stove, the frog’s body adapts to the water as it heats and the frog will cook without jumping out of the pan. Many families are in situations that are gradually heating up, and, because the escalation has been so gradual, they have not noticed how much hot water they are in.

This book is written for caregivers. It does not talk about how to give care. It is not a manual on the decision making this care demands. The one focus of this book is you taking care of you. If your name is caregiver then you are dominated by the very disease you fight. Just as in the woman’s story, you talk about your loved one, you talk about the disease and its progress and probably never notice what the disease and the care are doing to you and your world. If this book reaches its objective, you will have at least noticed.