



When Love Gets Tough

Care Decisions for Loved Ones



Doug Manning

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In-Sight Books, Inc.
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Preface

When this book was first published in 1980, my mother-in-law had recently died in a skilled nursing facility. Since that time my father has died in the same facility and my mother died in an assisted living center. Having written the book did not take away the pain of having to make the tough decisions about their care.

As I revised the book this year, I realized that the struggle will always be the same. I may know a few more stories to tell, but the heart of the matter is that due to the lengthening of our lives, many of our loved ones will live beyond our ability to care for them. I promised my parents they would never be residents of a nursing home. I kept the promise. They just outlived the promise. When that happens we face decisions we never wanted to face and we do so in spite of promises, in spite of intentions and in spite of what we want to happen.

Fortunately, we have many more options today than we did when this book first appeared. There is a whole continuum of care available for loved ones. There are facilities to meet almost any need and condition we face—from retirement centers, Alzheimer's programs, assisted living centers and, of course, skilled nursing facilities. The choice is still not easy, but the fitting of the care to the need does bring some peace of mind.

As a fellow struggler, may I wish you the very best with the decisions you face.

Doug Manning ✨
February 2006

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Section I

Making the Decision

*L*ove is doing
what people
need—
not just what
they want.
Love is doing
what people
need—
not what we
want.

1

Love Is Doing What People Need—Not What They Want

I wish I had a nickel for every time I said, “My folks will never go to a nursing home.” My exact words were, “There is nothing wrong with nursing homes, but neither my parents nor my wife’s parents will ever be residents there. They will have a home in my home for as long as they live.” That was my boast. My mother-in-law died in a nursing home. My father died in a nursing home. My mother died in an assisted living center. Life turned my pledge into an empty promise I could not keep.

Life also forced some rather drastic changes in my thinking. I am not alone in having to face this kind of changed thinking. Most of us never intended to place a loved one in a care facility. Most of us have made statements similar to mine, only to be forced to face the unreality of our boasts. It is not an easy change to make. It is never made without guilt and fear.

My change came gradually. It began with an observation. Our neighbor could not face the thought of her mother going to a nursing home. Her mother was bedridden in a coma and required constant care. These folks had to build a new house

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to accommodate the needs of her mother. Fortunately, they were financially able to construct such a home.

After the house was built and the family settled, it became evident that the wife could not handle the demands of care on a full-time, twenty-four hour basis. She had to have some relief. The answer for her was to get a job to get out of the house at least part of the time. The wife went to work, and a nurse was hired to take care of the mother during the day.

This provided some relief during the day, but the wife's schedule was still almost more than a human could bear. Five days a week she worked at a full-time job outside the home and then returned to be the homemaker and the night nurse until time to go to work the next day. On week-ends she was the full-time caregiver.

I watched the effect of this plan over a period of four years. The wife did not have to face the guilt of placing her mother in a home, but the cost of avoiding the guilt was giving up her whole life. She believed with all of her heart that she was doing all this for her mother. She may have been doing it partly because she could not face the guilt of a hard decision.

The husband was also affected. He had very little life of his own. The house became his whole world. There could be no vacations, no nights out, no weekends off. Every decision had to be made in light of how care could be provided for the mother. The mother's life had limited quality. Her presence in the home diminished the quality of life for everyone else.

Perhaps the most tragic figure in this drama was the wife's father. The neighbors lived next to us for several months before I knew the father even existed. His whole life consisted of sitting in a room next to his comatose wife and watching

television. He had no one to talk with. He participated in no social activities. He just sat and withered away. We moved from the city before the story ended. I always thought the father would probably die before the mother. He seemed dead already as far as any quality of life was concerned.

There I was with my vow to never place a loved one in a nursing home while living next door to an example of the real burden and impact this vow could cause. My thoughts began changing.

The final change in my thinking came when we moved my mother-in-law into our home. She stayed only one week. One week convinced me that my decision was not in the best interest of my mother-in-law or my family. My mother-in-law came to the same conclusion and suggested that something be done.

Nothing in our house fit the need. Our bathroom doors would not allow entrance to a wheelchair. The bath fixtures were not equipped for an elderly person.

We found ourselves tensely walking on eggshells. We could not be noisy. Our meals were not the right type for her. Since both my wife and I worked, my mother-in-law was left alone with no social contacts day after day. Her friends were miles away in the town she had lived in for many years. She faced a lonely existence.

It became evident we could not meet her needs—not even the evident physical needs. Nor could we provide for her emotional or social needs. Our world failed to match her world and her needs. We wanted to meet them. We loved her deeply; she was a dear lady.

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It became evident to my wife and me that we had to make a decision based upon her mother's needs. The decision could not be based on making us feel good about ourselves. We had to face the fact that no matter how much we might care, or how much we wanted to help, we just could not provide for the special needs of our loved one.

Love is doing what people need—not just what they want. Love is doing what people need—not what we want. In spite of what she wanted or what we wanted, we decided the best option was a nursing home. A nursing home could provide what we could not: Round-the-clock nurses on duty, specially designed bath facilities, social contact with people with similar interests, and activities designed for people her age and her condition would be provided for her.

We found a nursing home in our city. The home was equipped and seemed to have all the facilities she would need. Before we made the final decision, she had to be hospitalized. After a lengthy stay in the hospital she was moved to the nursing home. She was involved with us in making the decision and agreed that it was best.

It was still not easy. The nursing home seemed to be a strange setting for all of us. The roommate presented a problem. The adjustments we all had to make were still ahead of us. The only thing that helped us was the knowledge that we had no other option if her needs were to be met.

We clung to the idea that love is doing what people need. If we loved this lady, we had to make this tough decision and live with it.

On the surface it seems that love would mean we would care for our loved ones at home no matter what the cost. This

might be true if the cost was ours alone. The fact is, the cost is not ours alone. Living in someone's home may also cost the loved one. It usually costs them their privacy. It can cost them social contact. It can mean their physical needs are not met. They may never recognize their costs. They may never agree with the decision. They may never see the wisdom of these decisions. When they do not understand or agree, we still must make the decision based on what is best for them as we see it.

It is not an easy decision under the best of circumstances. It is a terribly hard decision when the loved one does not agree. The only comfort I found, and the only comfort I could give, was for us to concentrate on the needs and provide for them.

About the Author



Doug Manning

Doug's career has included minister, counselor, business executive, author and publisher. He and his wife, Barbara, were parents to four daughters and long-term caregivers to three parents.

After thirty years in the ministry, Doug began a new career in 1982. He now devotes his time to writing, counseling and leading seminars in the areas of grief and elder care. His publishing company, InSight Books, Inc., specializes in books, video and audio productions specifically designed to help people face some of the toughest challenges of life.

Doug has a warm, conversational style in which he shares insights from his various experiences. Sitting down to read a book from Doug is like having a long conversation with a good friend.