
*Determining
and Safeguarding
“What’s Best”*

Chapter 1

What Is It All About?

Derailed



“It’s not as bad as it looks, Terry!” I was home from Washington for Thanksgiving 1983 and Leila greeted me at the door with those reassuring words. Not as bad as it looks? It looked pretty bad to me. Leila had two black eyes and a painful back injury. Her glasses were taped together. She had fainted the evening before.

Over dinner, Leila confessed that she had been fainting occasionally for more than a year. Once, her neighbors had pulled her out of the backyard bushes. She not only hadn’t told me about these “little problems,” she hadn’t bothered her doctor with them, either.

Leila, 77, had struggled with health problems before, but this was where I said, “Life is now officially out of control.” I had to do something about it before it got worse—for Leila and for me.



I did “do something about it,” for the next 12 years. For much of the time, especially at first, I battled for Leila’s survival and my peace of mind. Her health problems were a nightmarish mix of

- ▶ fainting spells, the side effects of medications.
- ▶ permanent memory loss and confusion, not caused by Alzheimer’s disease, but probably by small strokes.
- ▶ congestive heart failure (Leila’s heart was not pumping efficiently).
- ▶ high blood pressure.
- ▶ a devastating bone disease, osteoporosis, that caused Leila to suffer multiple fractures. Brittle bones and fainting spells form a terrifying partnership. The worst injuries were painful “compression fractures” up and down her spine.

These health problems generated many crises. Outside forces were in charge of our lives. I worried about Leila. I worried about myself. I wondered if I would ever calm down and get a good night’s sleep. I wondered when I would start living my own life again.

Back on the Tracks

Gradually, surprisingly, life got better for both of us. Life improved because Leila remained motivated to “keep on going” and I learned how to take better care of her, and myself. However, we would have remained derailed had we not learned a vital lesson: We needed help. That help came from many sources, but none more important than the kind of assistance many elders will not accept: caregivers in their homes.

Leila and I learned that “eldercare” is about much more than “being taken care of.” We learned that it can be a powerful force that transforms, and often saves, the lives of frail older people. It can preserve the mental and physical health of their family members, as it did for me.

Ultimately, with lots of assistance, I was able to help Leila enjoy a fulfilling life in our home despite her physical disabilities and the memory disorder that stole her ability to manage everyday decisions. My life became simpler, less chaotic and often enjoyable. We regained control over our lives and with that control came peace of mind.

If I knew at the start what I have included in this guide we would have been back in charge of our lives sooner, more of my mother’s last years would have been good ones, and I would have enjoyed much more sleep.

Keep the Flame Burning

The brighter the flame of motivation burns, the greater the power to make it through tough times.

At first, I thought that once things go wrong as you age they inevitably stay that way. I didn’t realize Leila’s life could get better again. To prepare for the dismal future I learned about medical services, in-home care, Meals on Wheels, wheelchairs and safety bars for bathrooms. It was useful to learn about them, but our situation didn’t turn around until I understood that the key to staying in control of our lives as we age rests within ourselves. That key is motivation. If you can keep your parent’s spirit alive, you can accomplish remarkable things.

I also learned how important it is to work at keeping your own flame burning. If you don’t, you will lose control over your life, harming other relationships and your job performance. If you burn out, your parents are in trouble.

Remember: This is a *guide* to helping you do what is possible in your situation. It is not meant to make life more stressful if you can’t go to the lengths that I did.

Try to Rekindle a Dimming Flame

Leila’s love of life was the force I could call on when things were bad. Not everyone is as fortunate. I hope this guide will help you revitalize the lives of parents whose motivational flame is burning low.

Preserve the Quality of Each of Your Lives

To see what is “best,” look for what it will take to keep life as good as it can be.

Assisting your parents to retain quality and dignity in their lives is the key to maintaining the flame. It keeps hope alive. With hope comes strength and remarkable power. Remembering what life was like when it was good—and seeing what it could be again—kept my mother and me motivated in times of crisis. “*Let’s get out of this hospital and have lunch on our front porch*” worked more than once to get Leila back home and on her feet.

Once Leila was home, the desire to *remain* on the front porch kept her motivated to stay as strong and healthy as possible.

I made sure our lives were as normal and enjoyable as they could be. We had small dinner parties, went out to eat and took short trips. I had some social life, went on brief vacations and did other things to keep my spirits up. To preserve the quality of my life, I could not simply set it aside and live for my mother.

Being old does not mean you lose the right to decide what makes life worth living or the right to keep on living. Be cautious about deciding for an older person what “acceptable quality of life” means. You may decrease the quality of that life and put out the flame of motivation.

Even in the Darkest Times, Stay Focused on Quality of Life

Leila found that having me and other friends with her in the hospital made even the worst moments more tolerable. Life occasionally even seemed normal because we were with her. Some of you may be facing hopeless situations. Your parent may have advanced Alzheimer’s disease or be in the late stage of some other terminal illness. The support and love you provide your parent in those circumstances will mean more than you can know.

Try to take pressure off yourself in heartbreaking situations. Sometimes improving quality means reducing stress and anxiety. This guide will help with this difficult task.

Many times throughout the “Leila-and-Terry Years,” I was unable to follow my own advice. I would confide in close friends that I didn’t see how I could keep going much longer. Usually, with their encouragement and after a good night’s sleep, life looked better. The good times and the bad times taught me what I have included about coping with stress and anxiety in “Getting Strong Enough to Handle It,” page 51.

I have never regretted those years. I still think of them with a sense of fulfillment. I hope this guide will help you find this sense of fulfillment as well.

