

# **Keep the Flame Burning – Eight Rules**

**By Terry Lynch**

*Author's Note – Simon Duffy and I met at the 2008 International Conference on Self-Determination in Detroit, Michigan. We participated in a panel discussion on self-determination and aging. In my remarks I referenced the Eight Rules that underlie my strategies for helping older people retain their dignity and independence. I am honored that Simon then asked me to write this essay for in-Control.*

*My strategic approach to empowerment includes guiding the reader to essential resources found on the web sites of many government and non-profit web sites in the United States. I include some of them in this essay but, of course, cannot provide much of the relevant information you will find on the web sites of similar agencies and organizations in the United Kingdom.*

## **On-the-job training**

In 1985 I left my federal government job in Washington, D.C. and returned to Wisconsin, my home state, to start an independent living consulting business. I specialize in helping older people and people with disabilities remain as self-reliant and involved in community life as possible. Soon after starting my business I was living my work. It was then that my real education in “independent living” began.

Until her mid-70s, my mother, Leila Lynch, had been vigorously involved in life in Wisconsin. I will refer to her as “Leila” (pronounced Lee-I-Lah). Leila was raised on a Wisconsin farm and was known as “a high-spirited girl” who rode ponies bareback on the Erickson family farm.

Leila moved to Racine, Wisconsin at 21, where she met and married my father. When I was born, Leila left her job as an elementary school teacher and remained at home to raise me. When I began high school she returned to teaching. Then she moved on to a contented and active retirement with my dad. After he passed away, Leila adjusted as well as one can and went on with life.

In her late 70s, Leila's strength and vitality began to erode. She had several injuries from falls. During my last two years in Washington, she spent her winters with me. When I returned to Wisconsin, Leila and I became housemates in our family home in Racine, a small city on Lake Michigan between Milwaukee and Chicago. Leila remained somewhat self-reliant while we were in Washington, but shortly after we moved back to Racine more injuries and a rapid decline in memory stole her ability to manage everyday life. I was no longer just a son. I also was my mother's caregiver.

For several years, I battled for Leila's survival and my peace of mind. Her health problems were a nightmarish mix of fainting spells, memory loss and a devastating bone disease, osteoporosis, which 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. At times, 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.

Then gradually, surprisingly, life got better for both of us. Ultimately, with lots of assistance from caregivers, friends and neighbors, and excellent physicians, I was able to help Leila enjoy a fulfilling life in our home and my life became simpler, less chaotic and often enjoyable. We regained control over our lives and with that control came peace of mind.

### ***We kept the flame burning***

Before this revelation, I thought that once things go wrong as you age they inevitably stay that way. After all, wasn't this "what happens" as we get older? 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, home modification, assisted living and nursing homes. *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, even in difficult circumstances, rests within ourselves. That key is the flame of motivation – the power of the human spirit.*

Throughout those desperate first months, Leila remained determined to "keep on going." Her courage and love of life were the most powerful "long-term care resources" underlying this remarkable transformation. Several times early in those "Leila and Terry Years" the power of Leila's spirit and sheer luck got her through life-threatening crises. The flame continued to burn brightly.

Over time, I came to realize that hazardous myths and misconceptions contributed to many of these crises. Fortunately, I also learned Eight Rules that countered their destructive power and helped me keep Leila's spirit alive, even in difficult circumstances.

## The Eight Rules

These Rules can help us all keep life as good as it can be even in difficult times. Their power has been reaffirmed many times through my experiences with other families.

### Rule #1 — “Old” Is Never an Acceptable Explanation

A new acquaintance told me about his grandmother, who had injured her hip so severely she could not walk safely even after physical therapy. The family and her doctor didn't want to put her through surgery because she was 82. She moved to a nursing home and used a wheelchair to get around. His grandmother lost interest in life. Her appetite diminished. Everyone was worried.

A new doctor took her case. He asked her why she hadn't had surgery to get back on her feet. She said she was too old. He told her she wasn't. Her heart was still strong. Rob remembered telling her, “*Grandma, you could live for years. The doctor knows what he is doing. Where do you want to spend those years?*” She listened to Rob and her children and took the physician's advice. When I last saw Rob his grandmother was walking again and living in her own apartment.

This Rule applies to many situations — for instance, when we consider telling an older person “*You should not do this anymore*” even though she may have no significant problems with health, hearing, vision or mobility. “This” could refer to living at home, driving, taking vacation trips and other situations where safety becomes an issue. Check yourself. Why do you suggest this change? Is it strictly because of her age? If so, think it over again.

### Rule #2 — Prevention and “Old Age” Do Belong in the Same Sentence

**Don't ignore the obvious.** As the media reminds us constantly, exercise and a healthful lifestyle can prevent many crises that hit us in old age, including strokes and heart attacks. Leila's caregivers and I helped her walk as much as possible to keep her strong enough to avoid more injuries from falls. She ate healthful meals. Now and then we talked her into doing safe “weightlifting” exercises approved by her physician.

Leila's experience demonstrated what research has been telling us for some time: Even frail elders with chronic illnesses and mobility problems can benefit from *carefully supervised* exercise.

**Practice preventive healthcare** Today, there are screening tests and treatments for osteoporosis, the disease that caused Leila's bones to fracture. Nevertheless, many people, particularly post-menopausal women, have experiences similar to Leila's. They are unaware that they have this disease until it is too late to prevent the life-changing

injuries it causes. There are screening tests for many other diseases that become more common as we age.

**Work at becoming a savvy healthcare consumer** Physicians who emphasized preventive medicine and those trained in geriatric medicine were invaluable allies for Leila and me. Nevertheless, the more I learned about options for treating Leila's medical conditions, the better her health became. It helped me ask good questions and make useful suggestions.

Physicians sometimes don't find out right away about advances in the treatment of various diseases. Doing some research may teach you something your doctor does not yet know. For instance, a friend sent me an article on a new treatment for osteoporosis. I told Leila's doctor about it. He checked it out with a colleague and started her on a medication that increased her bone strength and reduced her pain.

I found the Internet web site of the U.S. National Institutes of Health, [www.Medlineplus.gov](http://www.Medlineplus.gov), to be a remarkable and consumer-friendly resource on every health-related issue I discuss in this article.

**Watch the medications** If Leila had known that fainting spells might be a side effect of her blood pressure medication, some of her worst injuries and longest hospital stays could have been avoided. Medication side effects or harmful interactions often underlie life-wrecking events.

Some health problems are caused by medications that have been prescribed inappropriately. Many older people have prescriptions from more than one doctor. This can lead to harmful treatment decisions by a physician who is unaware of this situation. Remind your parent to take all her medications with her on visits to physicians she is seeing for the first time. If she will take them with her every time she sees a doctor, new or not, even better.

Adverse reactions to prescription drugs such as dizziness, dehydration, and loss of appetite can lead to devastating consequences, including falls, depression, confusion, hallucinations and malnutrition. The web site of the National Center for Complementary and Alternative Medicine has extensive information on herbs and dietary supplements that can have harmful side effects and adverse interactions with medications. Visit: [www.nccam.nih.gov](http://www.nccam.nih.gov).

**Prevent injuries from falls.** Helping Leila avoid falling accidents was one of my most anxiety-producing concerns. Falls are the leading cause of accidental death among Americans age 65 and older. Many older people who suffer hip fractures will never return to their homes.

Many of these devastating falls occur at home. Relatively simple modifications can reduce the risk of these accidents. They include improving lighting, removing scatter rugs, and making sure floors are not slippery. For Leila's protection, we carpeted every

surface in our home, including the kitchen (not shag.) We even put outdoor carpeting on our front porch.

*There is specialized physical therapy for people with balance problems.*

Difficulty with keeping one's balance should be approached as a medical problem, not as a normal part of aging. *Always* see a physician when these problems occur. *Always* be suspicious of medications' side effects or harmful interactions.

The web site of the U.S. Centers for Disease Control and Prevention provides a Falls Toolkit with a checklist of prevention steps to take and hazards to avoid. Visit: [www.cdc.gov](http://www.cdc.gov). Search for: Falls Toolkit.

### **Rule #3 — Not All “Alzheimer’s Disease” is Alzheimer’s Disease**

A friend asked me for help with finding “a good nursing home” for her mother, who was experiencing memory loss and confusion. She assumed that her mother, who was 82, was in the early stages of Alzheimer’s disease. I suggested getting her mother a thorough physical examination before considering a move. She did, and, as a result, her mother was able to remain in her home. Treatable diabetes, not Alzheimer’s disease, was causing her confusion.

Life-altering confusion and loss of memory are not normal or inevitable aspects of aging. Alzheimer’s disease is not always the cause. It is one of a group of brain disorders known as “dementia.” Symptoms of dementia may be caused by other, treatable, medical problems such as alcohol abuse, depression, vitamin deficiency and adverse reactions to medications.

Do not ignore early signs of dementia. Always obtain an informed diagnosis. Never assume that you know the causes. Stay updated on what we are learning about slowing and preventing the onset of Alzheimer’s disease.

### **Rule #4 — Loss of Interest in Life Is Not Normal at Any Age**

Depression is an *illness* that sometimes accompanies the losses in old age, for instance the death of family and friends and decline of physical abilities. It is often associated with other illnesses such as Parkinson’s disease and cancer. Depression frequently is misunderstood. For instance, someone who has had a “negative personality” throughout life may have been suffering from depression all along.

Depression is *not* a normal aspect of aging. It is *not* a sign of “weakness.” Depression often can be treated successfully. Understanding this disease and recognizing its symptoms can literally save an elder’s life. The suicide rate for Americans over 65 is disturbingly high.

Leila was fortunate. She never experienced depression. Her disabilities and physical discomfort, however, brought her occasional “down days” that could have multiplied in less-supportive circumstances. Her mental health depended on more than “taking good care of her.” While her caregivers were helping her bathe, fixing her lunch, or simply sharing a cup of coffee with her they would talk with Leila about their boyfriends, their families, their everyday lives. They and I would remind her that her wisdom and insight helped us manage life’s problems.

Encourage your parents to remain involved in activities that add meaning to their days. Leila had been an excellent cook. Just talking with her about her famous meatloaf recipe and having her mix the ingredients helped her “still feel useful.”

### **Rule #5 — Rehabilitation Is Not Only for the Young**

Leila was hospitalized with a fractured pelvis a few months after we moved back to Wisconsin from Washington in 1985. She was 79. Because she was injured so severely, I feared that Leila’s life would never be the same again. I called Dr. Swenson, an acquaintance who specialized in the medical care of older adults. I told her my fears and how helpless I felt. She told me: *“I have seen badly injured and very ill older people rehabilitate quite nicely with time. Don’t give up.”* With this hopeful advice in mind and with physical therapy at home, Leila recovered and went on with life.

Don’t count your parents out when they are down. They may well be capable of “rehabilitating quite nicely with time.” Skilled physical therapy often works wonders even for people well past 90. Many older people with significant medical, mobility or sensory problems can remain quite self-reliant. They can stay in control of their lives, as long as they —are able to use good judgment — and as long as we let them.

*I learned not to make final judgments about a person’s rehabilitation potential during a hospitalization or nursing home stay. When we reach old age, institutional environments often become extremely disorienting in a short time. Leila’s coping abilities, memory and motor skills inevitably improved as soon as she was out of the hospital.*

## Rule # 6 – Preoccupation with Safety Can Be Risky

My Aunt Alvira was unconscious for days, most of them in a nursing home. Her doctors thought she had suffered a stroke. Then “Alvira’s miracle” occurred. She woke up. Because she was tough and stubborn, Aunt Alvira returned home, over the protests of family members, including me.

A nursing home social worker helped Aunt Alvira find what she needed to remain relatively self-reliant. She paid a neighbor to assist her with bathing, shopping and laundry. A nurse checked on her weekly.

I visited Aunt Alvira after she returned home and was shocked. She moved around by staggering from doorjamb to doorjamb, stopping to lean on whatever piece of furniture she found in her path. I covered my eyes when she went upstairs to bed. She would cling to the railing and haul herself to the top, stair by agonizing stair.

I tried to talk Aunt Alvira into sleeping downstairs. “*Aunt Alvira, why do you insist on going up those stairs every night?*” She replied: “*Well, Terry Boy, because that’s where my bedroom is. If I get tired on the way up, I rest. It’s the only exercise I get. Please don’t try to take my stairs away from me.*”

I surrendered and stopped bugging Aunt Alvira. She continued to haul herself up those stairs, to enjoy watching children play in the schoolyard across the street, and to host tea parties for her former piano students. They sometimes brought their children. They always brought her pleasure.

Aunt Alvira lived liked this, stubbornly and contentedly, until she left us one day as she sat in her favorite armchair, watching children play. Aunt Alvira was 94. It had been six years since her escape from the nursing home.

At first, I thought that what I was learning from Aunt Alvira was specific only to her. No one was going to tell her how to live her life, so we might as well let her live it. I finally realized she was teaching me much more than that. She was giving me a graduate course on the dignity and power of being “allowed” to live with life-saving risk.

Aunt Alvira’s choice would not be the right one for everyone, especially older people who are more fragile and less determined than she was. But it was undoubtedly the best choice for Aunt Alvira. She would have been miserable anywhere else. Her home kept her alive.

***Be a cheerleader.*** *Knowing you are with them all the way can be a powerful energizer for frail older people who can continue living on their own with some assistance. A few months after Aunt Alvira “converted” me she told me, “Thank you for being in my corner. We need cheerleaders.”*

## Rule # 7 — Your Parents and You Are the Experts

Throughout the hospital stay that I described in Rule #5, Leila could not stand without two people assisting her. While I agonized over what to do after she was discharged (“Rehabilitation hospital? Nursing home?”) she would tell me *“Just get me home. I will be OK.”* Up to the time Dr. Swenson assured me that Leila might well “rehabilitate successfully,” I was certain I would not be able to take Leila home until and unless she was back on her feet.

Leila and I decided to go home and see what would happen. I scheduled 24-hour care and left on a short business trip. I checked in periodically. Leila was making some progress but still required two people to help her stand. When I returned, there was Leila, *walking* to the living room, one person at her side. *“Mom, you’re walking!”* She looked at me with a quizzical smile. *“How else can I get to my armchair?”* I did not question her logic.

I marveled that Leila knew the solution to this problem all along. *“I will be OK once I get back home.”* This experience changed our lives and was the foundation of my approach to the crises that followed. Whenever Leila was hospitalized, I would focus both of us on getting back to our living room and our beloved front porch. It worked for nine more years.

*If you make decisions without considering what keeps your parents engaged in life, the results usually will be unfortunate — for your parent and for you.*

Age, frailty and illness do not add up necessarily to “unable to decide what is best.” Once their family members listened to Leila and my Aunt Alvira, things went well. Sometimes, as in Rob’s story about his grandmother, we have to assist our aging loved ones to see what is best by helping them see what is possible.

Don’t expect professionals such as physicians or staff of residential facilities to decide how and where your parents should live. They are often valuable allies but their job is to provide services and discuss options, not tell you what to do. No responsible physician or other professional would suggest otherwise.

There are many situations in which children must become the “experts” on what a parent should *not* do. For instance, had I been unable to ensure Leila’s safety at home, I would have had to try to steer her toward other kinds of living arrangements.



Sometimes you may have to accept a parent's unwise decision with potentially nightmarish consequences and hope for the best. Old age, alone, is not reason enough to strip him of the right to make a poor choice. However, if a parent is no longer capable of understanding the implications of his decisions you might have to resort to a guardianship proceeding to protect him from harm.

### **Rule # 8 — The Labels Must Go**

Leila and I learned that age discrimination is not limited to employment. Labels such as “*aging woman with dementia*” often blurred the fact that my mother was Leila Lynch — a person with feelings and rights. These kinds of labels made life more difficult for both of us. Sometimes they made life hazardous for Leila. I don't mean to imply that anyone labeled her purposely. It's just how it was. I know. I was one of “them” at first. It took a caring doctor who saw past Leila's labels to set me straight.

A few months after our return to Wisconsin, Leila was injured while I was traveling. Soon after entering the hospital, she began physical therapy. She told me over the telephone how painful it was to walk. I thought she wasn't able to understand that the therapist knew what was best for her. The labels “*old*” and “*confused*” controlled how I saw this situation. I told Leila to stay tough and not “baby” herself. However, when I returned I saw how agonizing it was for Leila to walk. I stopped her “therapy” session and went looking for answers.

Before I could request more tests, her physician, Dr. Johnson, who had been out of town, stormed down the hospital corridor. He was furious. “*I ordered additional x-rays. They have been walking your mother on a fractured pelvis!*” He apologized profusely. I asked him why he ordered the x-rays. He looked at me as though he could not understand my question and replied, “*Leila told me she hurt.*”

If others are to do well by our parents and not extinguish the flame of motivation, we must make sure our parents' best interest is never blurred by harmful labels.

#### **About Terry Lynch**

Terry Lynch is the Owner of Strategies for Independent Aging LLC, Racine, Wisconsin, USA. He has been advancing the independent living cause since 1977, when he served as Assistant to the Director of the White House Conference on individuals with disabilities. He then played a key role in developing what is now the National Disability Rights Network.

Terry's book, “*But I Don't Want Eldercare!*” — *Helping Your Parents Stay as Strong as They Can as Long as They Can*” is published by The Legal Center of Denver, Colorado and is available at [www.amazon.com](http://www.amazon.com) and [www.barnesandnoble.com](http://www.barnesandnoble.com). Terry's essay on making informed long-term care decisions under pressure is featured on the web site of the PBS documentary, “*Almost Home*”. You may reach Terry on his web site, [www.agingindependence.com](http://www.agingindependence.com), and by email at [tplynch45@gmail.com](mailto:tplynch45@gmail.com).