

# Living at Risk

by Cindie Smith



I have many clients who express fear and frustration with healthcare providers who fail to see the risk of an aging parent living independently. As a caregiver, I have felt that fear. Am I missing something? Is there a resource that could make the care recipient's life safer? How can they be so calm knowing that disaster is imminent? It's kept me awake many nights too, frustrated by a healthcare system that doesn't seem to recognize the danger all around.

As a caregiver myself, I struggle to remember that there are some things we simply cannot, and should not, control. I understand that we live in a time when awareness of autonomy is increasing; you can't just step all over someone's wishes because they are old, ill, or frail, even if greater demand on the caregiver results from a fall, a fire, or medication error. I've also considered that part of the rising tolerance of risk is that there are fewer hospital and long-term care beds and that the economics of health care is likely a contributing factor. The system simply cannot meet the needs of everyone, so people are triaged and those with the highest need are served first.

Alice is a long-distance caregiver to her 100-year old mother. She shared with me her worries over her mom living independently in her small house, with the bedroom on the second floor accessible only by narrow and steep stairs. Although frail and experiencing some cognitive decline, Mom can state the risk and the consequence of the risk of living on her own. Mom is feisty and

sharp in both wit and in criticism of those who try to tell her what to do.

It's taken a while, but Alice has made peace with the likelihood that Mom will have a catastrophic fall. Alice acknowledges that if there is a fall it may mean death. In fact, she hopes that Mom would not linger with a life-long injury because out of her element she would suffer.

Instead, Alice chooses to shift her focus. Every day that her mother gets to live by her own standards and wishes is a 'bonus day' and one to be celebrated. Rather than waking up to a day filled with worry over something she cannot control, Alice holds the worry at bay and celebrates the end of the day when no catastrophe has been reported. It's another day that Mom has lived under her own terms and didn't die.

Atul Gawande, in his book *Being Mortal*, writes: "I am leery of suggesting the idea that endings are controllable. No one ever really has control. Physics and biology and accident ultimately have their way in our lives. But the point is that we are not helpless either. Courage is the strength to recognize both realities. We have room to act, to shape our stories, though as time goes on it is within narrower and narrower confines. A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life ..."