

Introduction



In 2000, I became a family caregiver for a very short period in time—65 days, to be exact. In the fall of 2000, my bright, active, and independent 84-year-old mother became ill with a urinary tract infection (UTI). This was correctly diagnosed at the emergency room of a local hospital. What was not diagnosed was the delirium that was caused by this infection, even though disease-induced delirium is common in the elderly. At the time her illness began, Mom lived in her own home with my youngest sister, Jill. Despite the best efforts and intentions of Jill, our other sister Betsy, and myself, Mom died only 65 days later. This book is written with the hope that you, a family caregiver, or you—a “baby-boomer” whose health may impacted by common and preventable conditions, will avoid the tragic result that occurred with my mother. Knowledge is power. If you can learn the simple preventative measures that can prevent medical and medication errors for yourself or a loved one, then my mission will be complete.

The symptoms of Mom’s delirium—visual and auditory delusions—led to a psychiatric hospitalization. There, drugs that are dangerous to the elderly—antipsychotic drugs that interacted with her medications for her Parkinson’s disease and blocked their healthy effect—led to serious complications. The complications caused by the drug-drug and drug-disease interactions were misinterpreted by her doctors and nurses. They were understood to be a worsening of her Parkinson’s disease, and were not interpreted as medication errors or medication interactions. She declined rapidly. Her body systems failed. Since none of the medications she normally took and none of the medications that the facility prescribed for her to “cure” the symptoms that were observed were eliminated or reduced, her kidneys could not fully eliminate the many drugs going into her body. She died, then, because she was “poisoned.” The primary cause of death listed by the pathologist on the autopsy report was “toxic encephalopathy”—brain death—death caused by her brain being overwhelmed by toxic substances so that it could not enable her normal life processes to continue.

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I subsequently learned that Mom died because of several developing complications that commonly affect the elderly, whether they live in their own home, a caregiver's home, or a long-term care facility. I learned that these complications are predictable, often caused by a medical or medication error, recognizable, treatable, and preventable. I learned that early detection is key to successful treatment, and prevention is the goal caregivers must strive for. I also learned that a family caregiver can be and must be the first line of defense for her elderly loved one.

My mother's last days were horrible, and her death was very traumatic for me, primarily because I felt so responsible. After all, I'd made the choices—or participated with my sisters in making choices—that had led to her death. I set about to figure out exactly why she had died. After all, she'd only had a minor UTI. What I learned is that when an elderly person becomes ill, very often complications of the illness itself, or complications arising from a treatment or a medication, can cause something like a domino effect. There are so many ways in which one problem can quickly create another and another.

I've since been impelled to share with other caregivers what I've learned about six common and often fatal conditions that affect the elderly so that other family caregivers can avoid the tragedy that befell our mother and our family. My research revealed to me that Mom's death was caused by a progression of problems that could easily have been prevented: (1) delirium, (2) medication errors, (3) adverse drug reactions, (4) dehydration, and (5) malnutrition. These five complications commonly cause death in the elderly. Falls causing injuries are a sixth common cause of death in the elderly, and all six are preventable! These six potentially fatal medical problems are thoroughly presented in this book.

My mother's urinary tract infection was diagnosed in the emergency room of a hospital in the city where she lived in mid-Michigan, a three-hour drive from my home. Subsequently, she was confined and treated in a local nursing facility, spending two weeks in a psychiatric unit, two weeks in a medical, and almost three weeks in a "rehabilitative care" unit. Thus her care was provided by four different medical teams—all doctors and nurses who did not know her—and there was no continuity of care. I had no way of knowing then how vital continuity of care was in properly assessing and diagnosing Mom's emerging symptoms and how, as a result, lack of diagnosis and appropriate medical care caused serious conditions to escalate and overwhelm her body.

My sisters visited Mom every day. I talked with her on the telephone every day, but I saw her much less frequently. It soon became apparent that

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Mom was not improving and was, in fact, getting much worse. I asked the staff about many of her symptoms showing her decline. But when I questioned the nurses about them, I was told repeatedly that these changes were “to be expected,” that Mom was “debilitated,” and that there was “nothing that could be done.”

Looking back, it is fair to say that Mom was treated as many elderly persons are today: she was written off. There was a pervasive attitude among the caregivers I encountered in the long-term care facility that the patients were old and were going to die anyway, that caring for them—changing diapers, hand-feeding—was something that the workers did, not because they liked to do it, wanted to do it, or were even particularly good at it, but because they needed the minimum wages that are paid for these unpleasant jobs.

I decided to transfer Mom to a nursing facility near my home so that I could have more direct access to her and help with her care. I did not realize how critically ill Mom was on the morning I picked her up to take her to Traverse City, nor did the doctors or nurses tell me. The nursing facility had done lab tests that morning. Had they reviewed them, or had they even provided me with copies of them, perhaps things would have worked out differently. Those lab tests, which I found in Mom’s medical records after her death, revealed that she was so critically dehydrated that she should have been transported immediately to a hospital.

Why weren’t my sisters and I more forceful or more adept at getting proper medical treatment for Mom? At the time she was admitted to the nursing home, my sisters and I thought it best to leave her care to the staff. We were intimidated because we had no particular knowledge of geriatric medical matters and we assumed the staff had critical knowledge we did not possess. We did not realize that these doctors and nurses, like most doctors and nurses, had no training at all in geriatrics, as Dr. Friedman explains in Chapter One. Sadly, we did not appreciate the importance of our intimate knowledge of Mom’s usual mental acuity and her normal physical abilities and limitations. Nor did we realize how our assessment of changes in Mom’s mental and physical condition, if communicated to her medical caregivers, could have led to diagnosis and treatment of critical, emerging, fatal conditions. In particular, we did not realize that our communications of changes in her status to nurses were minimized because the nurses’ assessments were based only on what they saw, and were not seen in perspective with observations made a few weeks earlier when she was in the care of a different team.

What I now know could have saved my mom’s life and may save the life

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of your loved one.¹ I now know that the primary caregiver is the person most likely to know when a loved one needs medical attention. I thought Mom's doctors and nurses were monitoring her care. I was shocked when my research revealed that a person living in a nursing home may see a physician *once a month for five to 15 minutes!* That same person may have some attention daily from a nurse, either an LPN or an RN, but usually LPNs and RNs spend *less than one hour per day* per resident. Much of that time is spent doing indirect care such as writing nursing notes or preparing medications for distribution. Residents of nursing homes do get about two hours of care per day from a competency evaluated nurse assistant (CENA), but CENAs are typically responsible for the care of 12 to 14 residents in an 8-hour shift and are not trained in medicine. They are usually entry-level employees with minimal training and experience. They not only lack the education and training to detect signs of medical complications, they haven't the time to look for them.

The elderly patient, if competent, is in the best position to detect that something is wrong, that something has changed in her condition. If she is unable to communicate effectively or to understand and appreciate changes in her condition—if, for example, she is suffering from dementia—then a family caregiver who undoubtedly spends more time with her than her medical caregivers is the best person to detect these changes, even without special training. A family caregiver who sees something different about the way a loved one is functioning physically or mentally can and should tell a primary care physician and follow up with an appointment.

While my sisters and I were intimidated by our lack of medical expertise and by what we thought to be the complexities of Mom's medical treatment, I have since learned that there are tools and knowledge that family members can use to help keep their elderly loved ones healthy and safe. After a great deal of research, I have been able to understand how ordinary—how common, in fact—Mom's medical problems were and how capable we might have been in helping her caregivers assess changes in her condition. I have come to appreciate the critical role a family caregiver can play in early diagnosis of medical conditions and, more importantly, in

¹ Recognizing that the person for whom you are a caregiver may be your parent, grandparent, or spouse, and sometimes an adult child, the term "loved one" is used consistently. To avoid continuous awkwardness, the pronouns "she," "her," and "hers" will be used rather than constructions like "him or her." Indeed, since most family caregivers are themselves 60 or older, the information in this book will apply to their own healthcare as well.

the prevention of these medical conditions. In my case, what I did not know hurt my mom and resulted in her death from terrible and preventable conditions.

This book is my gift to you and your loved one: the easy lessons I learned too late, the lessons that would have saved my dear mother, and the lessons that could save your loved one. I want you and your loved one to be spared the suffering and death my mom endured and the loss our family experienced as a result.

If you are caring for an elderly loved one, or if you are 65 years old or older, *Taking Charge: Good Medical Care for the Elderly and How to Get It* will give you the information and tools you need to form an effective alliance with physicians and caregivers. Let me emphasize that medical training is not required for this task.

Let me also reassure you that my goal in this book is not to convince you that nursing homes are horrible dungeons that the elderly must avoid at all costs. Many elderly persons experience healing, productive stays in a nursing facility when recovering from surgery, stroke, or other illnesses requiring hospitalization, rehabilitation, and recuperation. However, nursing homes do have, in general, some serious shortcomings—notably a lack of adequate staffing, which you will read about in Chapter Eight. To protect your loved one from the possibility that understaffing may result in harm, you need to know when to sound the alert that will bring assistance from physicians and nurses and how to work with them to prevent your loved one from falling victim to common preventable medical complications. Your willingness and ability to enter into an alliance with the physicians and the nurses overseeing your loved one's care will make you a valuable asset to her medical caregivers.

I believe you will find the information presented in this book, if frightening at first, enlightening and empowering over the long haul. Each chapter is organized to help you to recognize the symptoms of these common conditions and to understand why your loved one is at risk for them. Armed with this vital information, you will be able to describe changes in your loved one's status to her physician so that early diagnosis and treatment can prevent her downward spiral and early death. Most important of all, prevention is key to your loved one's health. The information provided here will help you minimize the risks and prevent the onset of common complications that can pose a significant threat to your loved one's health and life. My goal is to give you the tools you need and to encourage you to have the confidence needed to communicate effectively with your loved one's medical caregivers.

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Endnotes containing the medical journal articles I relied on are found at the back of the book so that you may determine the source of statistics and other technical information. If you want more detailed information, your local librarian will be able to order any of these articles for you. Many of the sources upon which I relied are available on the Internet. I've provided the URLs for these. I found some articles to be so valuable and so universally relevant that I placed references to them in Appendix P as "Recommended Readings." You will find other appendices helpful as well. All appendices are available without charge on the Internet where they may be read online or printed out. The primary reasons why these materials are available on the Internet is that they are more useful to you as 8- by 10-inch pages that you can three-hole punch and keep in a binder as part of your loved one's "care-giver's record," and also there are many hyperlinks in the appendices which will make it easier for you to access the tools, the articles, and the associations to which you will be referred.

As a lawyer, I have always told my clients, "Knowledge is power. What you don't know can hurt you." Use this knowledge to prevent harm to your loved one.

*March 1, 2006
Old Mission, Michigan*