

HELPING OUR PARENTS



**How to be an Effective
Healthcare Advocate**

Michael J. Guy, J.D.

Copyright © 2018
by Michael J. Guy, J.D.

All rights provided under the U. S. Copyright Act are reserved by the author. 17 U.S.C. §§ 101—810. Other than brief quotations used in critical articles and reviews, no portion of this book is to be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or by any information storage and retrieval system without prior written permission of the author.

Although the author has made every effort to ensure accuracy, we assume no responsibility for errors, inaccuracies, omissions, or any inconsistencies.

CONTENTS

Introduction.....	v
1 Why Advocate?	1
<i>(Examples of Healthcare Advocacy, some effective, some not)</i>	
2 Be the Medical Historian	27
<i>(Medical Records, how to get and use them)</i>	
3 More than Paper	45
<i>(A perspective on medical documentation)</i>	
4 Informed Healthcare Choices	67
<i>(An in-depth look at Advance Directives and beyond)</i>	
5 The Rest of the Paper	99
<i>(The Durable Power of Attorney and its friends)</i>	
6 How to Advocate, Part I	127
<i>(Who you'll be working with & how to play it)</i>	
7 How to Advocate, Part II	159
<i>(Solid examples, good advice & some simple tips)</i>	
8 The Dying	197
Afterword	219
Disclaimer	221
Works Cited	223

Introduction

My wife, Jennie, and I were watching an episode of the television series *Blue Bloods* starring Tom Selleck. Selleck's character, Frank Regan, is the commissioner of the New York City Police Department. The Regans are portrayed as a very close, educated, successful and influential family. Even the grandson, a patrol officer, has a Harvard Law degree. Selleck's character and his father (played by Len Cariou) live in the same house. His father is a retired NYC police commissioner. They eat meals, watch sports, drink or talk about cop family matters in most of their scenes. In this episode, Selleck's TV dad has suffered a heart attack. Once gathered at the hospital, the doctor addresses the family, "first of all, I need a list of his medications." Police Commissioner Regan (Selleck) responds with, "I don't know. I should know this", which is delivered with a dimpled yet severe look of humbled frustration.

It was only a few seconds of a scene in a TV show, but it portrays where most of us are with the idea of helping our parents navigate the medical industry in their later years. When you have your *Magnum* medication list panic attack, anything you say or do other than

immediately producing the requested current list is insufficient.¹

Janet, my mother-in-law, spent over a year in the Boston Massachusetts medical centers while recovering from heart valve replacement surgery and its complications. During that time, Jennie pretty much moved to Boston and was with her mother every day.

Jennie really missed our dog, Deuce, and maybe me a little too. On the weekends, Deuce and I'd drive to Boston to see Jennie and Janet. As soon as I was within 20 feet of the nurses' station one or more of the staff would eagerly greet me and offer up where Jennie and Janet were in the facility and what they were doing.

While walking by that nurses' station and being instantly updated, I'd often see another person there to visit a loved one. "Is my mom still in room 304?" the family member would ask. "Let me check. What's her name?" was the typical response from the nurse typing at the keyboard. Which patient do you think receives the better care?

Because Jennie was there helping her mother, the folks in the hospital had a heightened awareness of Janet and thus were engaged with her care to a greater degree than other patients. I realize it's probably not practical for you to put your entire life on hold and move to Boston, but there is much that you can do to fully engage the medical folks if you have the knowledge to correctly prepare and do the most with the time you have. Preparation and consistency are the keys to being an effective healthcare advocate.

You will work with medical professionals that will respect your efforts and, if you are truly effective, they will come to rely on you as a valuable part of your loved one's care. You will also find that you are going to be a major irritant to some in the medical industry and they will not be shy in letting you know it.



We can meticulously plan for our later years in fiscally responsible ways that have zero possibility of protecting us from the true frustrations of aging and illness. Our leaders create laws that are thousands of pages long, written in our nation's finest politically malleable legalese. Laws can't protect our parents' dignity in a medical facility or nursing home. The sad fact for the majority of us is that we will one day find ourselves tearfully exasperated and alone with one or more of our basic needs not being met for at least some period of time. It will not be the result of any form of intentional neglect or elder abuse. It will happen simply because when you are relying on others for care you are depending on human beings, overworked and imperfect, just like you. Don't let the insurance company, senior housing, skilled nursing or medical facility salesperson standing in front of the camera or in the glossy extra heavy stock literature fool you, they can't do a damn thing to insure that Dad will not someday be helpless, in need of care and stripped of his pride at some point. It does not matter how many times you tell yourself that his nursing home, hospital or rehabilitation facility is "the best". Regardless of their work ethic or workload, those caring for Dad know that ultimately a patient without someone to help them and monitor their care can wait longer.

Not everyone becomes permanently dependent on strangers. I am sure there are kind loving families that care for their loved ones in their family homes, bedside, with the warm and fuzzy feeling we had for the television Waltons. The vast majority of medical professionals and workers do sincerely care much more often than not and some even put forth a level of compassion that makes them the true living angels that they are. Sadly, families like the Waltons and angels are

the exceptions. In Dad's moment of lonely realization, when his adult diaper is soaked, smelly and he just coughed up the cold tomato soup that he spilled the other half of on himself, the angel will be on vacation, on break, or having a bad day when he pushes that call button for the countless time in what is to him an eternity. Your loved one will never be the highest priority of anyone but you.

We don't plan for, or even think about, how it will be to see our parents, any loved one, or ourselves become increasingly vulnerable and dependent on others due to illness or simply the natural aging process. There may be nothing that we can do to truly prevent forms of human error, excusable neglect or even the outright abuse of every senior entrusted to the care of others. We do, however, have the power to stack the odds against it happening to our parents by getting involved in helping them manage their care, advocating for them, and caring for them with the loving compassion that we expect from others.



Productivity is crucial in any business, be it manufacturing, a non-profit food pantry or your local hospital. If a doctor and supporting staff can see more patients in a day, they are fiscally more productive. The result of that inevitable economic pressure is that when Mom goes to an appointment and the doctor comes in the room 30 minutes late, typing on a laptop, they are either completing notes on the patient they just left in the other room, hoping spell-check will help them to pronounce her name or locate the most recent test results in her file.

When you go to a meeting at work, you have to prepare and be ready to offer the best input you can. Doctors don't have that luxury in today's cost conscious medical environment. They have to quickly skim the most recent page and a half of Mom's records to refresh their

memory, interpret test results, maybe do some form of examination, make critical treatment decisions, explain it all to her and hope to make something close to an accurate notation of the visit in the notes, all in roughly 20 minutes—while under the pressure of the several other folks sitting in rooms waiting to have him or her come into their room late typing on a laptop. What are the odds of your parents (or anyone) with two, three or more medical conditions, coming out of that appointment with a solid understanding of what’s going on?

What the Heck is Healthcare Advocacy?

Jennie and I were the primary caregivers for our parents from the time we became aware that they needed our help until they died. Three of them were able to die in their homes. In managing their medical care and the care of others, through short and long term illnesses, we have alternatively worked and jostled with medical workers, administrative individuals, insurance providers and family members. We have shared countless experiences, joyful and horrendous. Along the way we’ve accumulated a fair amount of practical experience for two laypeople functioning in the procedurally and technically complex medical industry.

Within a few months of opening our elder law office, we became aware of an unanticipated need that law school did not prepare me for. Clients would come in for an initial visit and we’d spend less than half of the time talking about elder law. Once the conversation turned to documents related to medical care, it grew to more than just “what paperwork do we need for Mom?” The clients we meet with have a thirst for knowledge that goes beyond having the correct

estate planning documents in place and hoping to avoid selling the family home, camp and spending Mom and Dad's life savings to pay for long term care.

At some point while managing our folks' medical care, we started informally asking medical personnel, at all levels, for input on how to best help our loved ones. We talked with nurses, doctors, specialists, case managers, medical administrators, insurance professionals and the maintenance staff about how to help our parents. The response was enthusiastic and respectful from much of the medical community. All either said they have been such an advocate for their loved one(s) or they are prepared to be one when the time arrives. Healthcare advocacy by family members is needed and patients with effective family advocates receive better care. When asked how to best help Mom and Dad, nobody in the medical profession could tell us how to be a healthcare advocate, but they were clear that Mom and Dad need one.

We had taken copious notes of those conversations as well as amassing other healthcare related materials over the years. We went back to the boxes of paper and computer files, summarizing it all in an effort to create an outline or simple document to guide clients when helping their patents. It quickly turned into a bit of a research project. We assumed there had to be a wealth of material to guide folks on how to navigate the medical industry for Mom and Dad, information that we just did not know about.

We contacted area hospitals hoping to meet with them to discuss the process of helping our parents navigate the medical industry as they age and approach death, what we had started calling healthcare advocacy. Only one had the time. We were privileged to meet with

several department heads and even the CEO of the organization. They provided excellent insight into the way they operated and their experiences with families trying to care for their elders. The information clearly helped us to define some of the paperwork issues that a budding advocate would have to deal with and we did hear their perspective on the family members' role in their parents' healthcare. Ultimately, we were able to validate the way we had cared for our folks and the material in our notes, but did not get a copy of that healthcare advocates' secret manual that we hoped for.

The next effort was to write many letters to geriatric and family medicine doctors. We received one response. It was from my parents' doctor who had retired at that point. She was very nice and gave me a good hour of her time.

I asked her about how family members should tactfully engage with doctors and nurses to help their parents understand and manage healthcare issues. It was clear the topic was foreign to her. After working to formulate an opinion, having been put on the spot, she settled on "Mike, you did a good job with your parents." She had seen that I went to appointments with them, explained things and was respectful of her staff. She had no idea that there was a plan in place and that I was not just giving Mom or Dad a ride to the office and sitting in during the visit.

She then volunteered a story about the end of her father's life, explaining that her father died from complications that could have been mitigated or avoided and that she wished she had engaged more in his care. I found it interesting that when trying to advise me as to the best way to help our elders navigate the medical industry that her mind would immediately go to a personal story that involved death,

medical errors and her own regrets.

One of the letters went to my doctor. When I saw him several months later, he had the letter with him and we discussed it. He made comments on things like medical treatment paperwork and other things you'll read about later. He too volunteered a personal story. It was about the death of his mother that involved a challenge for him as the advocate.

His mother had been sick, it seemed like the end of her life was near and she could no longer make her own decisions. He knew his mother's choices for end of life care but the rest of the family was not so clear. There came a point when it was questionable as to whether a specific type of treatment would be something she would choose to have. The discussions escalated to the point that the only way the family could agree was to go on a treasure hunt for some document that could help them. Fortunately, they did find an old medical form in her house that was sufficient to settle the dispute.

Both medical professionals had on the tips of their tongues personal examples of the challenges that face someone who advocates for their parents' care but neither had a conscious awareness of what a healthcare advocate is. Everyone agrees with it, but nobody knows what it is or how to do it.

The next step in trying to find some clear direction on how to help folks effectively advocate for Mom and Dad was to start reading more than a few books, periodicals, journals and spending countless hours with online databases of all things medical and legal in an effort to learn what the professionals have to say on the subject. I did not find anything even close to a succinct guide for those of us trying to help our parents. There are many books about healthcare written in the

self-help style to simplify and explain the medical system to laypeople like us. They are very accessible, written in easy to follow prose, packaged and marketed very attractively. They sell a lot of copies. Others are academic works of such density that you need a dictionary, a thesaurus, high-speed internet and a lot of coffee to get through the introduction. They don't sell a lot of copies. Don't be scared. The authors and readers of the academic material are safely tucked away in faraway places of higher learning.

The research provided some clues and the occasional tip for someone taking care of Mom and Dad, but not the advocates' handbook that we really need. The research then turned into a sort of healthcare advocacy reading of books, scholarly articles, and policy papers written by doctors, lawyers and nurses.



Most of the commentators seek to solve a big problem. Some call for a need to change the way doctors think, the way they are trained, or a global change in the way the business of healthcare operates. All of the issues are important but they have nothing to do with you not having Dad's medication list when the doctor asks for it. The issues they write about could someday, if corrected, help your parents but that's just too far removed from what they need now. Most of the problems these commentators bring up can be resolved (or worked around) at the Mom and Dad level, today, by an effective advocate. Healthcare advocacy will not fix the acknowledged problems with healthcare. It will help Mom and Dad, but it cannot be done by doctors, lawyers or medical workers with the next wave of trendy administrative titles on their business cards. You have to do it.

Janet

The patient you'll be reading the most about is Janet, Jennie's mother. A retired teacher and breast cancer survivor, she was a most vibrant life force. More than anything, Janet loved her children and grandchildren. Having them around was about as good as it got in her world. When that was not possible, shopping and travel were good substitutes.

Janet suffered a long and complex series of illnesses. Life events aligned in such a way that Jennie was able to act as her primary healthcare advocate and caregiver in the years prior to her death. The complexities of Janet's conditions took them through multiple hospitals, over a year in an acute care rehabilitation hospital and close to a year of 24x7 hands-on care in Janet's home. Janet's story is the extreme. Most of us will never experience a fraction of what Janet endured, nor will we be a tenth of the advocate and caregiver that Jennie is. It is from the overwhelming enormity of their shared experiences that we have many good examples for you to read and learn from. There are several other characters in our stories, but Janet is the one you'll get to know the best.

Jennie & Mike

We were born, raised, live and work in Kittery, Maine. Jennie is a retired civil service Human Resources/Administrative Officer. She is an experienced bookkeeper and legal secretary. I have worked in retail, as a bridge troll (gatekeeper on a drawbridge), founded and operated a small technology business and, for my mid-life crisis, went

back to finish college and then to law school. Together, we operate an elder law office and teach classes in healthcare advocacy at local adult education programs.

While I may have compiled these words, every example of advocacy that shows model character, compassion and guts is all Jennie. The lessons learned would not be possible without her leadership.

The stories you'll read are true but most of names have been changed out of respect for the heroes' privacy and to protect the mediocre, the ignorant and the guilty.

The title was originally going to be *Helping Our Parents Die* but we thought it best to drop those last three letters. I didn't want to be mistaken as someone promoting their opinions regarding euthanasia or offering a punk perspective on end of life healthcare. The title was softened, but in a way, death is the end result of your work as Mom and Dad's advocate. If you take the time to truly get it right, you will improve their quality of life when they need you most, when they are old, sick and at the end of their lives. You really can help them die, or should I say, have a better death.

The purpose of the book is to provide a process for how to be an effective healthcare advocate for Mom and Dad. There are stories combined with light research that supports both our experiences and ideas. I have tried to make it accessible and somewhat entertaining. There is a lot to being effective at this. No matter how much or how little you can do, focus. Take the time to prepare and then be consistent in your efforts.

An unanticipated benefit of our efforts has been that we have enjoyed more meaningful relationships with the loved ones we've care for, a level of connection that we had no idea existed, one that we

never would have experienced had we not taken the time to slow down and get involved with them, their care and their deaths.

We sincerely thank you for reading these words and hope they are useful as you help the ones you love. If you take the time to care for them with all the preparation, compassion, consistency and love you can muster, we assure you a tremendously meaningful and rewarding experience that will change you forever.