

Chapter 1. Why you need this book

Over the past 10 years, we've heard countless health professionals and families say, "If I had only known about your program, it could have saved me such grief!" Upon hearing these statements, we wondered, "What is it about our program that makes a difference?" Much of what we do is about helping patients and families understand their story of aging and death, which often leads to a new approach that is more empowering and enriching. Yet, as much as we try to help others, our experience with patients, caregivers, and healthcare providers have become a treasured collection of learnings that increase our knowledge and skill. We have experienced the power of these stories and their lessons, and we're honored and eager to share them with you.

A common thread that runs through our stories is that most people don't die early or suddenly, but instead experience a progressive decline in their health that can last for years. A tipping point occurs when health declines to the point where routine tasks become a struggle and begin to threaten the person's very sense of self. Circumstances in this phase of life often bring up a life's worth of challenges, often with complicated family dynamics. This time of life can be confusing and chaotic, disappointing and isolating. Many healthcare providers don't want to acknowledge these difficulties, and as a result people can feel even more bewildered and alone. Even for the most well-adjusted person, the losses and uncertainties can be overwhelming.

If you're struggling with the experience of caring for a family member or friend with complex health issues, we hope this book and our message can offer support and guidance. We will talk about how to understand what is happening in the life stage we call frailty. We'll take you behind the scenes into the world of health care delivery. By building knowledge and getting a better idea of what you'll encounter along the way, we hope that you may be better able to cope with some of the challenges you'll encounter.

Throughout this book we use stories to validate your experience. We hope you can engage with the stories in this book and consider the experience of others, along with your own, through a new lens. What's working? What's amiss? What can we learn and what can we do better?

We believe in the power of conversation and deep reflection as tools for finding the best path forward.

Christine's story:

As our family confronted the challenges associated my dad's declining memory and health, everything became difficult: It was a struggle for him to keep up with life's demands, and a struggle for us to accept and deal with what was happening. Once a distinguished and accomplished CEO of a large insurance

firm, my father now had memory loss related to Alzheimer's dementia. His behaviour during outings was difficult to handle—flirting with strangers and becoming upset over the availability of creamer at the local coffee shop became regular occurrences. At times, my father expressed quiet dismay and at other times open anguish, such as when he was unable to recall his banking PIN number or the names of his grandchildren.

But if the cognitive changes seemed like a bad dream, dealing with the healthcare system was a nightmare. It was hard to keep up with the litany of appointments, tests, treatment recommendations, and instructions. The elephant in the room was never discussed—that despite diligently tending to my father's health, he was getting worse, not better.

Besides the dementia, dad was also in the throes of treatment for bladder cancer. Every six months, he and my mom made their way to the urologist's office for three weekly treatments, which were injected directly into his bladder. This process was meant to continue for 3 years. In order to determine whether the cancer was progressing, the urologist regularly looked into the bladder with a scope.

The treatments were described by the doctor as straightforward, but they were not easy. Without fail, after every treatment, my father became agitated and upset. He was incontinent and couldn't follow the instructions for how to avoid exposing he and my mom to the drug. As urine leaked out of the Depends my father wore, my mom became more anxious as she tried to keep things together.

With each treatment, my dad took a permanent hit to his wellbeing. He just couldn't bounce back before the next treatment was due. Mom was stoic and supportive, but I knew she was struggling.

The doctor encouraged my dad to continue the treatments and gave lots of evidence for doing so. He said the injections would delay the progression of cancer, would help dad live longer, and would lessen the chance of him needing surgery to remove his bladder entirely. Who could argue with that evidence? So, my parents agreed to continue, but mom had a nagging feeling that they needed a different approach. She and I wondered:

- Why were they painting such a positive picture of dad's health, when things were so clearly falling apart from our perspective?
- Why was the cancer taking center stage, when my father's failing memory appeared to be the more significant issue for his quality of life?
- Were we doing the right thing?
- Should we ask dad what he wanted to do? Could he even make that kind of decision?

Trust your instinct: the system *is* flawed

Christine's story is just one of many about how the healthcare system fails to provide holistic care to older adults who are frail. Chances are that the bladder cancer will never be this gentleman's dominant health issue, compared to the expected deterioration from Alzheimer's dementia. Yet, it became the major focus of care.

If you're reading this book, you've probably had similar experiences of providing care or support to someone with multiple medical problems who doesn't seem to be responding to the endless number of medications, tests, recommendations and appointments.

You're not alone. This book is for you.