



NATIONAL FAMILY CAREGIVERS ASSOCIATION

“It Doesn’t Have to Be This Hard”

The Healthcare Nightmare

An NFCA Commentary 7/07

My friend Fran* is living a family caregiver’s nightmare. As I write this, Fran’s husband, Bill*, has been either in the hospital or a post-acute facility for four months. Fran can count on one hand the number of nights she has made it home before 11 p.m.

Bill has been a high-maintenance diabetic for a long time. What I mean by that is his blood sugar level is erratic and so his insulin needs to be monitored and tweaked fairly often. He also has many of the co-morbidities (the medical term for additional chronic conditions) that typically go along with diabetes, such as high cholesterol and hypertension.

Bill sees multiple doctors — so many that the list sounds like a dictionary of medical specialties. He has a primary care physician, a cardiologist, an endocrinologist, a neurologist, an ophthalmologist, a podiatrist, a vascular surgeon, and a wound care specialist to treat his various conditions.

Bill had a triple bypass back in the mid-’80s. Subsequently, he’s also had two strokes and a seizure, resulting in some impairment of his right arm and occasional short-term memory lapses. His condition eventually resulted in him retiring earlier than he expected. Most recently, he developed a diabetic ulcer on his right foot that was not responding to medication despite many months of treatment. Eventually his foot began to swell and cause him great pain. Despite this, no new actions were taken. When Bill’s pain became unbearable, Fran took him to the ER; he was admitted to the hospital right away. The diagnosis: The ulcer was infected. And that is when the nightmare began.

There isn’t enough room here to give you a highly detailed description of everything that occurred, but this synopsis will give you a sense of Fran and Bill’s ordeal.

Shortly after Bill entered the hospital, the ulcer, which started as a small irritation of the skin, very quickly turned into a hole the size of a quarter that reached all the way down to the bone. Fran can’t help asking herself, “Why did this happen?” It’s not that she hadn’t taken Bill to the doctor, didn’t follow directions for medicating the ulcer. Unfortunately, she’s never received a good answer. One reason Fran thinks it happened is that many different podiatry residents were treating Bill. No one appeared to check the history of what went before, nor prepped the one who came after. It was like a revolving door, and the lead podiatrist wasn’t monitoring the case as fully as he should have been. It’s no wonder that Bill developed an infection that went undetected until his trip to the ER, and then progressed from cellulitis to osteomyelitis after being admitted to the hospital.

Fran was forced to become the unofficial coordinator of all of Bill’s care, keeping his primary care physician up to date, trying to set up actual team meetings, and watching the aides and nurses as they treated Bill because it was not uncommon for them to forget to review his chart for new instructions that might have been entered or to use the wrong medication on Bill’s wound. Fran was responsible

for coordinating Bill's care, but she didn't have the training necessary or the respect of the medical personnel involved. And all this was on top of her full-time job.

The long and the short of things is that the wound was not healing, no matter what was tried. The doctors huddled and presented Bill and Fran with bad news. The blood flow to Bill's foot was virtually nonexistent and things would be getting worse, not better, as more and more ulcers occurred. The prognosis was pretty grim. There was an operation that could possibly open an artery above Bill's ankle and restore the blood flow, but Bill was not a good candidate for it since two of his arteries were blocked with plaque and the third one that goes to the foot was too small. The medical team advised amputating Bill's leg all the way to the thigh. The other option was amputating pieces of it at a time as the problem progressed.

In this partial description you can easily see some of the numerous problems and frustrations that Fran encountered while trying to get good care for her husband. Here is a list of those and more.

- Residents without proper supervision, which led to mismanaged care
- Nurses not checking charts and therefore applying the wrong medication
- Nurses not checking charts and therefore forgetting to provide on-going everyday medications
- Healthcare by body part as opposed to treatment of the whole person
- Lack of consideration of the impact of Bill's diabetes on proposed treatments
- Medication interactions that caused Bill to lose cognition
- Bureaucratic runarounds instead of honest answers
- Bureaucratic runarounds because no one wanted to take responsibility
- A lack of a patient advocate until it was too late to do any good
- Extreme resistance when Fran said she wanted to get an outside opinion on the recommendation to amputate Bill's leg

Need I go on? Fran is a fighter and an amazing advocate for Bill. She finally prevailed, and, through a combination of cunning and good luck, was able to get a copy of Bill's medical records from hospital A and managed to get him transferred to hospital B.

The good news is that hospital B was able to operate on Bill and to restore blood flow to his right foot, the lack of which was preventing the healing of his ulcer and causing the intense pain Bill was experiencing. (Remember that hospital A didn't think this could be done.)

I've been listing out the problems Bill and Fran experienced in a straightforward and factual way, which does not let you see the anguish and frustration, the exhaustion, and the fear on my friend's face. Nor can you know the intense physical pain that Bill went through and his sense of utter helplessness. Ultimately, it was determined that although Bill's leg could be saved, his toes needed to be amputated. He was transferred a few weeks ago to a rehab center where a rather inconsistent medical staff needs constant oversight and Fran is afraid to leave until all treatments have been finished for the evening and Bill is going to sleep.

This is chronic illness care in America today — a workforce shortage and poorly trained personnel on the one hand, and well-trained but poorly supervised personnel on the other. Care is disjointed, at best, and there is little, if any, teamwork that addresses the patient as a whole. If system-wide coordination exists it is only because fiercely determined family caregivers like Fran battle entrenched practice and make it happen. Many things need to change in order for our loved ones to receive good chronic illness care, and one of the most important things is to add a care coordinator, or healthcare navigator, to the medical team, especially in complex cases like Bill's.

This person (or team of people) would be responsible for ensuring that all the other team members know fully their patient's situation and converse together regarding treatment options, with all of the variables and their implications on the table. The coordinator would be responsible for cutting through bureaucratic rigmarole to get things done in a timely manner. She would be an advocate for Bill across all settings — whether from one floor to another in the same building or across town to a different one — and then to home so that information is not lost during the transfer, something that occurs all too frequently today.

She would work in partnership with Fran to ensure that Bill gets the highest quality, safest care possible and the social support services he needs, and she would keep an eye on Fran to make sure that she is taking good care of herself.

There are some people who think that if Medicare paid for comprehensive care coordination services for its sickest members, so much money would be saved that Medicare would not have the financial problems it does. We won't know until we try, but it is the best chance we have for making sure our loved ones get the kind of care they need and deserve and that we, too, receive the care and support we need and deserve.

It's important for family caregivers to speak up about these issues and demand that the presidential candidates discuss their plans for improving chronic illness and long-term care. Now is our chance. Now is our opportunity to be recognized for the very hard work that we do. Now is the time to transform our healthcare system so that it is fully responsive to the needs of those with chronic conditions and their family caregivers.

**Names have been changed to protect the privacy of the individuals involved.*

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