Doing death better

In the national debate over health care, the way we die is the issue that few want to confront. A Milwaukee cardiologist makes a plea for Americans to face their worst fears and prepare for life's final chapter.

By Bruce Wilson, Special to the Journal Sentinel

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We struggle so with death. It frightens us and drives us, causes us as a culture to fight it with a vengeance.

Life is to be embraced. Yet death, whenever it comes to each of us, is as natural as the rising of the sun. We spend so much money and emotional turmoil staving off death, even for minutes or hours, beyond all hope, often beyond reason.

In our culture, we have some work to do in coming to terms with death.

As a physician, and particularly as a cardiologist, I have had to deal with death many times. Often in my business this comes quickly and unexpectedly, and little has been discussed ahead of time to help in this difficult moment.

My first experience with impending death, at least as a responsible party, came on my first hospital rotation as a medical student. I was assigned to a cancer ward at a university hospital. On my third day, the team was making the morning rounds. There were two students, an intern, a resident, an oncology fellow and an attending physician.

The patient was only 19. His name was Joe. He had a mop of dingy blond hair and large, haunted eyes. He had been in the hospital for weeks to receive an experimental treatment for metastatic (widespread) colon cancer that had little effect on his far advanced disease. He lay speechless in his bed each morning as the team came around and discussed his statistics. He never said more than a syllable at a time, and to my surprise the team seemed comfortable enough with that as we stopped for only a few minutes each day. On top of having a horrible and lethal disease, Joe was from a small town and must have been intimidated by all the hustle and technology of a modern university hospital.

On this warm day in June, one of the more senior doctors looked down at Joe and told him that the
treatments had finished and that he'd be able to go home the next day. It was quiet. Somebody told Joe that we'd get everything ready for his departure. That was it. I think someone asked him if he had any questions. Of course Joe said nothing, as usual. Those big eyes, and space. We walked out of the room. I was at the end of the pack. Joe spoke to me then.

"What's going to happen to me?"

I was shocked just to hear his voice, and felt horribly unprepared to respond. I told him that I didn't know all the details of his case and his treatment, and that I would speak to the senior doctors to try to get him some answers.

I went into the conference room where the others were discussing something clinical and told the attending physician what had happened, and that somebody needed to go spend some time with Joe.

He punted. "You seem to have a pretty good feel for these things - you go talk to him." It was absurd. A new third-year medical student three days into his first rotation being asked to speak to a dying patient about whom he knew almost nothing, not to mention knowing little about anything else, either.

I did go into Joe's room, and talked to him at length about his fears and about his impending death. It took all I had to look him in the eye. On my way out of the hospital later that day, I felt as if I had to get out and be somewhere private as I was holding back a flood of emotion.

I bumped into his mother on her way in, who asked me if it was really OK to take him home the next day. I held on. I got a block away from the hospital and was sobbing my eyes out while walking a mile to my car. I'm sure the people passing me wondered if I had lost my own brother.

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Back then, there was no training in helping the dying patient, or more importantly, their families. People are trying now, but there's so much more to be done. This is in part because medical science over the past 100 years or so has developed treatments and technologies so fast.

Generations of physicians like me have falsely been brought along thinking there's always something more we can do. As doctors, we often view death as our failure, a thought that remains subconscious because it's too disturbing to have right out on the table. We have given this notion to our patients and to society as a whole, as well. Many a family member has pleaded at the bedside of their dying relative, "There must be something you can do!" They've seen it so many times on TV.

Over time I would find myself as the medical director for a hospice, where I gained education in areas where I had only the guidance of my heart and my experience.

I know now how to manage and direct these conversations. They are often hard, but they are critical, and they are professionally rewarding. There is often nothing we can do for the patient in terms of technology. Our equipment wears out. Everything stops. But the time around someone's death will be remembered by the loved ones for the rest of their lives.

First, we need as a culture to view death as a natural end to a cycle. Mankind has been walking this Earth for about 200,000 years. Our 75 years or so on this big ball is but a speck on that timeline. Death is often viewed as a moment, and one to be feared. We should learn that death can be viewed as a chapter, and one in which spiritual and emotional growth can occur both for the patient as well as the
family and friends left behind.

Hospice refers to a way of delivering this type of care in the last chapter, when no more technology is appropriate. It helps get the patient into the frame of mind of making the proper internal adjustments for things to be right. Comfort measures and attention to psychological issues for all involved is of utmost importance.

Hospice care can occur in a hospital, in another facility, or in the home. It's a philosophy, not a place. Palliative care is really the same thing. It's a way of scripting the last chapter. We wish to avoid panic and fear while holding death at bay.

My own mother is slowly dying of progressive dementia. Her mother died of it while I was in medical school. The day I got into med school my mother told me that if she were ever to find herself without her mental faculties that I should give her the "black pill."

All of her advance directives and power of attorney forms were filled out years ago. Yours should be, too, regardless of your age. And far more important than the legal documents is the discussion with the people you love and who love you about what your wishes would be. And it's OK to change your mind from time to time, depending on what's going on in your own personal universe.

But talk about death. Share gratitude with the people who are most important to you, and tell them your thoughts. We can avoid much of the fear and prevent people from being put, often by the medical professionals who seem to view death as the enemy as well, into positions of responsibility and decision making that will haunt them forever, well after you're gone.

It's a chapter. Work with it. Write your own script. Don't fear it any more than you'd fear birth, or puberty, or retirement. Take part in it with the important people around you. If you are one of the ones who are gone in a split second, you won't have suffered, but your loved ones will. Spend some time while you're around letting people know how much they mean to you and what you would want in case you can't speak for yourself.

And then we have to tackle what to do with my mom, who made it perfectly clear a thousand times over.

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