

Op-Ed

By Ira Byock, MD

At a recent community forum at which I spoke, a woman related her family's plight. "My father was just admitted to the hospital. He is 80 years old, but despite an old heart attack and lots of arthritis pains, he's been fiercely independent. When we visited last night it was awful. He was lying half out of bed, wet from his knees to his chest and agitated. He said he had been ringing for help getting to the bathroom, but no one came."

In age and appearance, she might have been my sister. Indeed, I don't know anyone my age who is not dealing with some aspect of the care of a grandparent or parent or in-law. I waited for the poignant question I knew would come. "What can we do?" she implored.

Death is inevitable, but the way critically ill men, women and children die is a national disgrace. With all the technological advances, you would assume the medical field could assure them of being reasonably comfortable and dignified as they draw their final breaths. Instead, confused, impersonal, rushed and unreliable care often is what people get at a time when they most need comfort. Many Americans needlessly die in pain. Many also die poor, knowing their care consumed their family's savings and will leave a legacy of debt.

Caregiving is an issue that 78 million aging Baby Boomers cannot afford to ignore. A tidal wave of frail and elderly will swell the ranks of American nursing homes from 1.6 million people today to 5.3 million in 2030. Who's going to care for us? The shortage of nurses and aides is already dire in long-term care and the yearly turnaround rate for aides is 93 percent — little wonder when the average nursing aide makes \$7 an hour. Without some major changes, the nursing homes of tomorrow may make those of today look like luxury hotels.

What can we do? Most immediately, we need to attend to our families and friends. Those who are too ill or frail to speak up for themselves need advocates. My response to the worried daughter was straightforward: "Don't leave your father alone. Not even for a few minutes. Create a schedule and make sure that as long as he is unable to act or advocate for himself, one of your family is always with him."

"But what if they make us leave after visiting hours?" she asked.

"If the hospital objects, be polite, but persistent. Practice saying, 'I'm sorry, we're not leaving.' If that doesn't work, drop polite."

Advocacy of this nature is absolutely necessary, not because doctors or nurses are uncaring, but because the health care system is broken, and unable to respond to the needs of patients in decline, or their families. We all need to be assertive and proactive.

There is help out there for those who know where to find it. A handful of leading medical centers and health systems are testing new models of care that integrate curative treatment and palliative care, focused on improving quality of life. These approaches move beyond the artificial separation between life-prolonging and hospice care that is imposed by Medicare and private insurance. More than 20 state-based initiatives are working to remove regulatory and financial barriers to effective pain treatment, inject symptom management and end-of-life care into medical and nursing schools curricula and to support families in planning and in caregiving.

In literally hundreds of American towns and cities, committees have formed to educate local health care and civic leaders and address deficiencies in access and quality of services. Across the country, faith communities, senior centers and even schools are participating in volunteer efforts to check up on ill and frail, elderly neighbors and assist families who would

otherwise have to go it alone.

But beyond improvements in healthcare systems, fundamental cultural change is needed. Our expectations must be much higher and every individual and family needs to know what to do to meet them.

I draw hope from knowing that we boomers, while older, are still the "me" generation. We question authority, and accept only the best. In our twenties and thirties we transformed the way obstetrics was practiced. Today, no hospital is without a home-like birthing unit and Lamaze classes, and none fail to invite fathers into the delivery room. It is again time to take back responsibility for our loved ones' care.

A WWII poster of Rosie the Riveter hangs in my office, a reminder that we are not the first generation of Americans to face unprecedented threats to our society and our families. The challenge of caregiving will test us in profound ways. It is not borders or national sovereignty that we must defend, but the inherent dignity of frail and dying persons. It is not arms that we must raise, but standards of care and public expectations. Our tools are not weapons — they are our voices, our health care and insurance dollars, our letters, our petitions and our votes.

Use them wisely. In caring well for others today, we are also building a future in which we can all live, age and die well.

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