HEN DEATH COMES knocking now, it usually happens in a hospital or nursing home. We can’t just put on our bedroom slippers and slip out the back door because we are too often hooked to machines with innumerable tubes invading our bodies, and are infused with mind and body-altering drugs in order to “try just one more thing.” Unfortunately, all too often we die alone in sterile health care facilities. The cost of dying this way is so much more complicated than the poetic “striding” out the back door. Estimates for the cost of end-of-life care include numbers such as 27% of the Medicare budget, 10%-12% of the total health care budget, and 25%-40% of the cost can be saved during the last month of life with advance directives and hospice care (Emanuel, 1996). Byock (2012) notes only 25% of patients eligible for hospice care actually receive it and the average time spent in hospice is 3 weeks.

Missing in these financial data is information about what it means to patients, family, and caregivers to be participants in futile end-of-life measures. There are better ways. The literature is rich with evidence of practices that reduce the toll and suffering of patients, families, and the nursing staff. It takes extreme courage as a leader to implement evidence-based practices, and end-of-life is no exception.

Courage and End-of-Life Care

As leaders, we must feel a sense of moral obligation to implement evidence about end-of-life care in our practice settings. To do otherwise is to knowingly prevent patients and families access to the best care available, exposes our nursing staff to serious ethical dilemmas, and unnecessarily consumes valuable resources for futile care. Nurses in management and administrative roles regularly toggle between (a) the need to provide the best care for patients and families, (b) creating healthy work environments for nurses and caregivers, and (c) the obligations to perform well in the business aspects of health care. This is a difficult balance and must be attended to at all times to be a successful leader. End-of-life issues create great angst for leaders. This is where courage counts.

The courageous leaders in end-of-life care focus on four leadership pillars: (a) best care for patients and their families, (b) best care for the nursing and other staff who care for patients at the end of life, (c) developing systems that support the best care in end-of-life situations in our organizations, and (d) our communities and nation. We are not as good as we can be with end-of-life care. It will take the courage of leaders to advocate for implementing known evidence in the face of many obstacles within the health care system.

The Best Care for Patients and Their Families

We have far to go. However, there are options. For many patients and their families, death is treated as a failure and an unanticipated consequence of living. We prepare so little for such a meaningful event in our lives. By contrast, when babies are born, parents often spend considerable time researching and learning about the birth experience and come to us with defined birth plans and tell us exactly how they want to orchestrate that experience. Hospitals build very attractive units with the option of birthing rooms, midwives, and in some cases hot tubs and other alternative practices and rituals. By contrast, very few peo-
people come to us with end-of-life plans and advanced directives, and we seldom probe to determine how the patient really wants to die. We assign specialized nurses to the birthing process and other journeys through the health care system such as surgery or heart disease. However, we do not regularly have specific nurses as we do in specialized areas such as cardiac and oncology who are experts in the processes at the end of life to attend to the patient and family when the sacred cycle of transitioning from living to dying occurs. We have elegant birthing rooms but do not have a beautiful, special place for patients and families to celebrate the “passing.” Families withdraw because they don’t have the kind of skills that we provide people in the birth experience with prenatal classes. Often the patient is left physically and emotionally alone with a staff that can also be untrained and uncomfortable caring for someone in his or her last days. It doesn’t have to be this way.

We can help patients and families orchestrate a beautiful experience that is an alternative to futile, expensive end-of-life care. There are many options. For example, the Respectful Death Model is a research-based model that supports patients, families, and also the professionals involved in the completion of the life cycle (Wasserman, 2008). There is no need for patients to transition in efficient, high-tech rooms where it is often not acknowledged that the patient is in the process of dying. Keegan and Drick (2011) write about establishing golden rooms where patients, families, and caregivers can focus on the work of passing through this life in beautiful memorable surroundings. The opportunity to accept any and all visitors as the patient and family wish should be facilitated for making the birth experience a celebration vering through political traps and advocating for their work is what courageous leaders do.

Courage to Change the System

Sustainable change requires that people buy into the change and support it willingly with or without the leader. Mindsets need to be changed. Within the facility, the leader must engage many other principals to support best care for patients and staff at the end of life. The work includes creating trust and a willingness to work together in a system where the incentives are not aligned and personal, professional, ethnic, social, and religious values collide. Courageous leaders do not shy away from this challenge. A plan built around the best care for the patients can integrate with many diverse positions and people.

Changing Our Communities and Health Care System

The effective leader is not one who thinks of the unit or organization only. Communities, states, and our nation should ensure patients and families do not suffer and caregivers are supported. It makes no sense to have a best practice in one part of our system and people unwilling to share it with the rest of the world. Leaders must be involved in systems beyond their organizations to create sustainable change. For example, health care leaders in one community have taken the challenge of increasing the number of people with advance directives in their community very seriously. In Lacrosse, WI, the Gunderson Lutheran Health System initiated a program 20 years ago that has raised to 96% the number of people who died with an advance directive in place (Butcher, 2009). Now the program is implemented in many places nationally and internationally as the result of a few courageous leaders who made a commitment to change practice. With health care reform, the nation is crying for leaders who can develop thoughtful and workable solutions to help with individual choice. Now more than ever, it is important for nurses to be politically active to advocate for patients above the polarized views of politicians. Unfortunately, as Byock (2012) notes, the issue of end-of-life care has become politicized. Courageous nurse leaders are well adapted to maneuvering through political traps and advocating for patients and their families.

Summary

Many years ago foresighted nurse leaders advocated for making the birth experience a celebration directed by the family to include fathers, siblings, and
grandparents. Pediatric nurses see the family and the child as one unit and develop care plans for the family as a unit. Unfortunately, for someone at the end of life, we cannot guarantee he or she will have the same access to specialized compassionate care as babies who are birthed and children who are hospitalized. Brave nursing leaders had the courage to change the way we view obstetric and pediatric care. We have wonderful models to follow. It only takes the courage of nursing leaders to advocate for the voice of the patient and family and the nursing and professional staff in end-of-life care. Everyone benefits personally and financially, including our communities and nation, when courageous leaders advocate successfully for effective end-of-life care.

REFERENCES