Do you have an area of advocacy in nursing? Something about which you are truly passionate? For me as an orthopaedic clinical nurse specialist, my practice area of concern was always pain management. We have so many pain management strategies at our disposal as nurses that there’s really no reason a patient cannot achieve an acceptable level of comfort. Ah, but that’s a conversation for another time...

Right now, I want to share another, equally important area of advocacy with you. I am certain this will ring true if you have cared for dying patients (haven’t we all?) or perhaps have lost a loved one or close friend to terminal illness. The concern is how we as nurses discuss end-of-life (EOL) choices with our patients and their families. Nursing journal editors around the country and the world have united to bring this topic to the attention of our readers. As health care professionals who care for people from birth to death, we unite in suggesting nurses have a sacred trust. We must ensure patients are empowered to discuss EOL choices with their families and members of their health care teams.

The Institute of Medicine, now known as The National Academy of Medicine, released a stirring report in 2014, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life is essential reading for every health care provider. It affirms the critical role of EOL planning so providers can ensure the right balance – as determined by the patient – between quality of life and continuing intervention.

The Conversation Project

Even before the Academy publication, though, The Conversation Project was underway. In 2010, writer Ellen Goodman convened members of the media, clergy, and medical professionals to share stories of death with their group of loved ones. These included the so-called “good deaths” and “bad deaths.” Their conversation was the first, but the grassroots campaign has continued to encourage people to discuss their wishes for EOL care. In 2011, The Conversation Project began a collaboration with the nonprofit Institute for Healthcare Improvement (http://theconversationproject.org/).

Leaders in The Conversation Project believe, as I do, that only the patient can be the expert on EOL wishes. Not the nurses. Not the doctors. Not even family members. A starter kit is available on the Project website to help individuals have conversations with those who matter most to them.

- 90% of people say that talking with their loved ones about EOL care is important.
- 27% have actually done so. (The Conversation Project, 2013)

The site also contains amazing stories about how people started their conversations, or perhaps avoided them until it was too late. Either way, we can all benefit from their shared experiences. Please review and share the materials on this website, especially with your patients who are struggling to define their own ends.

Engaging Patients

Be an advocate who engages with patients and genuinely respects their wishes. Partner with them to develop a truly patient-centered plan of care. Document and communicate their expressed EOL wishes just as reliably as you do their other personal health information.

I’ll close with an eloquent plea...more powerful than any words I could offer.

Too many people are dying in a way they wouldn’t choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. It’s time to transform our culture so we shift from not talking...
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about dying to talking about it. It's time to share the way we want to live at the end of our lives. And it's time to communicate about the kind of care we want and don't want for ourselves. We believe that the place for this to begin is at the kitchen table – not in the intensive care unit – We can make sure that our own wishes and those of our loved ones are expressed and respected. (The Conversation Project, 2016)

REFERENCES