

Advance Care Planning Engagement: Meeting People Wherever They Are

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Mary, a petite woman in her 60s, arrived early for an advance care planning educational session at the local library. She listened attentively, asked pertinent questions, and took notes. Afterward she lingered, then shared her story.

She developed kidney disease in her 50s. While her condition was manageable for several years, she began to decline, and became dependent on dialysis.

She hated dialysis, with its long days, the lingering fatigue, dietary restrictions, lack of control, and the ongoing reminder of her dependence on medical intervention. She'd opted to put herself on the kidney transplant list, and was one of the "fortunate" ones who matched with a donor quickly.

Mary underwent the transplant surgery, which was a success, but her recovery was not quick, nor easy. In fact, it was often painful, exhausting, discouraging, and isolating.

With dark eyes flashing, she added, "It tested my faith and was just awful!"

Mary verbalized being eternally grateful to her donor. She added that, despite feeling pressured by her family and even her health care team, she resisted the idea of any more surgeries or life-prolonging interventions.

Her second and current husband wanted no part in representing her medical decisions. Her only child, a young adult daughter, was adamant that Mary "do everything" to "keep going," but Mary was unsure. In fact, she was in a quandary. She wanted to please her daughter and her health care team, but not at the expense of enduring what she had previously experienced with the transplant surgery and recovery. After much thought, internal turmoil, and lots of conversation with those closest to her, Mary resolved to select a close friend as her health care decision-maker. This was someone she trusted deeply, and Mary felt assured her friend would honor her choices.

Mary's situation is unique, but everyone's situation is unique. Hence, the fundamental challenge of community education for advance care planning. How do you provide sufficient information, in an hour or less, that gives attendees the understanding they need to make informed decisions reflective of their wishes? Most often, you don't.

Facing our own mortality is hard. Facing the mortality of those we love the most is often harder. We know from national data that only one-third of adults in the United

States have an advance directive in place, while 97% agree that educating patients and their families about these issues is important, which speaks to the challenges of engagement [1]. Seventy percent of us will die at the end of a chronic illness [1], yet we mostly don't want to think about, or plan for, our future frailty or infirmity.

Advance care planning is a *process*. It's not one-and-done; it requires consistent messaging from across the health care spectrum (doctors, nurses, social workers, chaplains, etc.), positive reinforcement, and multiple touch points. People typically come to multiple educational offerings over a span of time before they feel ready to complete their health care power of attorney, living will, and/or psychiatric advance directive documents. You have to make the process as supportive as possible for people, meeting them wherever they are, as they move toward readiness—reinforcing that these documents need to reflect their values and what's most important to them, and that telling their loved ones and health care providers is crucial to having their wishes honored.

Rare is the person who shows up ready to complete their documents, and when this happens, it's usually prompted by a painful personal experience. A husband and wife arrived at a recent educational event all ready with their documents. She explained, "My 42-year-old brother recently died after a heart attack and a long hospitalization. I don't want my family having to make the decisions I had to make for him. I want to get this taken care of now."

Our culture is shifting, though. More and more people are interested in learning about advance care planning and taking control of their future health care decisions. Bringing educational events to naturally occurring groups works well—whether that's a faith community, civic group, book club, workplace, or any other gathering. With the reality of COVID-19, this will now likely include virtual gatherings.

Some of the key things I've learned from the experience of hosting community education specific to advance care planning include the following: It takes courage for people to

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attend a community event to discuss their wishes related to end of life. There are no “right” or “wrong” choices when it comes to advance care planning. It’s all about understanding and recording each person’s values and what matters most to *them*. In order to set an appropriate tone, it’s important to be flexible and willing to tailor or adapt your presentation to the needs and interests of your audience, taking into consideration and aligning around any deeply held cultural and/or spiritual beliefs of the group. Framing key learning as a discussion rather than a formal presentation by asking open-ended questions and encouraging attendees to share their thoughts and/or personal experiences throughout, rather than waiting until the end, can encourage participation. This can occasionally take the discussion in a different direction than planned, but can lead to a richer, deeper dialogue and enhanced understanding by attendees. People often have concerns or even fears that are unique to their lived experience, and these are typically deeply personal, and therefore may be difficult for some to share publicly. For those who are willing and able to share their experiences, listening carefully and validating their perceptions and/or experiences is crucial to building trust and engagement. Avoid personal bias or judgment by staying curious. Stay afterward and

invite attendees to ask whatever questions they want.

Being entrusted with these most intimate discussions about choices specific to end-of-life care feels precious, sacred. It is a deep honor. I am thankful for the constant reminder that I receive more than I give in my role of supporting the very human desire to author life’s final chapter. **NCMJ**

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