

The planning pickle: managing advance care directives



By Melissa Weidman

Sara Drew is in a pickle. Though she's looking forward to retiring from her teaching job soon, her asthma's been getting worse lately, and she often feels run down. At the same time, her 88-year-old mother, Sophie, is recovering from a recent stroke which landed her in the emergency room. When the ER receptionist asked Sophie for her signed health care proxy form, Sophie simply replied, "I'm perfectly capable of speaking for myself, thank you!"

Sara is aware that the stroke has left Sophie far less capable. Sara knows she won't be allowed to make medical decisions for her mother without a signed health care proxy form. She had read some articles about advance care planning, and was surprised to discover that in Massachusetts the health care agent role doesn't automatically revert to next of kin. You have to intentionally choose and authorize someone you trust to speak on your behalf as your health care agent. More importantly, you need to have an in-depth conversation while you're both fully able, so your agent understands the choices you want advocated for your care and comfort.

When Sara tried to talk with Sophie about this, Sophie waved her hand, dismissing the whole topic and said, "I'm just fine, dear. We don't need to waste our time speculating."

As if that weren't enough, Sara's grown daughter, Sasha, agreed with her grandmother. "Oh Mom, stop being morbid! You're way too busy, and we'll deal with it when the time comes." Sara gave up trying, still having no idea what Sophie would want for care if she were incapacitated.

Sara is typical of her baby boomer cohort known as the sandwich generation. As they near retirement age, with many facing their own health issues, their aging parents are experiencing a longer trajectory of serious disease.

Their adult children are often unaware or in denial about the pressing importance of making sure all necessary paperwork is in place for their parents, grandparents, and even themselves, regardless of age or health status.

Fortunately, there's a trend of awareness about this issue among health care and social service providers in localities across Massachusetts. Cape Cod has been a leader in creating a community-wide solution. Cape Cod Hospital and HopeHealth are two Honoring Choices Partners spearheading this initiative on Cape Cod, offering free toolkits and local activities. The Quality of Life Management initiative is a community-based task force comprised of more than 50 local organizations.

The goal is to create a strategic plan for getting Cape Codders to talk about good health care all through their lives, have conversations about vital life-and-death issues, and address end-of-life care, particularly for chronically ill patients. Adult children may be unaware of a parent's preferences.

Who's Your Agent? is one important tool to make sure your advance care plans are known by whomever is your healthcare agent.

Fortunately for the Drews, Sara's primary care physician had attended one of the Quality of Life Management meetings and brought up the topic when he examined Sara for her asthma. He asked her about recent stressors and Sara shared her dilemma about her mother. He referred her to Cape Cod Healthcare's blog, where she was able to download all the forms. He told her about The Conversation Project's website where Sara could show both Sasha and Sophie videos of real families having planning discussions. They realized that having such conversations and taking care of these documents before another crisis came to pass would give them all peace of mind.

As Sophie said, "Well, I didn't want you worrying about me! But I guess there's a lot less worry this way."

And so, the pickle has been solved!

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