Family Matters—Dealing with DNA Legacies: Integrating Genetics, Genetic Counseling, and Hospice and Palliative Care (TH342)

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Objectives

- Describe the frequent occurrence of genetic issues at the end of life.
- Identify tools that can help one recognize genetic issues, refer for counseling, and suggest DNA banking or testing.
- Recognize practical ways to donate a body to science in most states.

Genetics, epigenetics, and genomics all play an increasingly recognized role in disease causation and progression. While upstream recognition of genetic-related serious illness is always preferable, an estimated 10% of patients dying in hospice or palliative care will have previously unrecognized genetic causes. The benefits of timely recognition and appropriate action—often right before the person dies—include offer of discussion about at least one the following: (a) saving appropriate DNA or other specimens from the person with the condition for future testing, before that opportunity is lost; (b) genetic counseling and testing for changes such as BRCA, Lynch syndrome, or cardiomyopathy; (c) counseling of the remaining family; or (d) being part of legacy or life review.

We will illustrate the possible actions to take with three cases: a 41-year-old woman presenting near death with advanced colon cancer; a 53-year-old man with congestive heart failure, three of whose four siblings have died from heart failure or had heart transplants; and a 55-year-old woman with dementia.

We will illustrate how to document in EPIC, as an example of an EMR, and consider the pedigree. All participants will have a usable list of available resources for DNA banking and testing.

In addition, we will illustrate the growing options for patients to donate their bodies to science at no cost to them through clearinghouses, such as LifeQuest Anatomical, MedCure, and the national registry of Body Donation Programs in the United States.