Advance Care Planning: Help for Making Care Decisions Now and for the Future

 By Mary Lynne Knighten on July 17, 2019No Comments

by Mary Lynne Knighten

Are you one of the 70% of people who does not have an advance care plan (ACP)? Advance care planning is the process of planning for future medical care. ACP is an ongoing course of action whereby patients, family members, and healthcare providers consider the patient's goals, preferences, values, and beliefs, discuss how this informs their health and medical care now and in the future, come to mutual understanding of how everyone involved honors the patient's wishes to meet their needs, and document future healthcare choices.

Planning in advance for decisions in the moment.

An advance care plan can be created at any age or stage of life. Whether a person faces an acute illness, a progressive, chronic condition, or terminal disease, advance care planning can help alleviate unnecessary suffering, improve quality of life, and provide insight into decision-making challenges a person experiences. ACP enables the person and his/her loved ones to "think through" what approach to take if—or when—the person's health declines. It is a dynamic process and requires ongoing conversations as the patient's medical condition or health status changes.

Ideally, ACP should be proactive, anticipatory, incorporated into routine medical care, and timed to maximize receptivity, engagement, and participation. ACP should include an examination of the patient's knowledge, fears, wishes, and needs—not just medical issues, but life goals.

Ensuring that wishes are honored and needs are met.

The goal of ACP is to ensure that patients' healthcare reflects their goals and values by engaging them (and family members, as the patient desires) in conversations to review their current condition, the future course of their disease, and their prognosis. Considering choices and what should and should not be done is the core of advance care planning.

Over time, loved ones may need to make difficult decisions in the best interest of the patient. A surrogate decision-maker should be chosen for the time when the patient is unable or lacks capacity to make healthcare decisions on his or her own. It is extremely important that patients express their wishes and goals for care and that the surrogate knows and understands their preferences. ACP provides a framework for informed decision-making for the surrogate, while reducing the burden they carry about whether the decisions they make follow the patient's wishes.

Tools for living and planning for the future.

Talking about your health and how you want your life to be isn't easy…but it is one of the most important conversations you and your loved ones will ever have. The Conversation Project, a collaboration with the Institute for Healthcare Improvement, provides a framework and toolkit to enable loved ones to communicate about future healthcare needs and bridge the gap between what people say they want and what actually happens.

An Advance Directive (AD) is not the same thing as advance care planning, but is another tool that can support ACP. Advance Directives are legal tools that provide guidance about the type of care and treatment you would want and designates a surrogate decision-maker should you be unable to speak for yourself. Advance Directives are only to be followed when the patient has lost the ability or capacity to make decisions themselves.

A POLST (Physician Order for Life-Sustaining Treatment), known by other acronyms in different states, is a medical order for the specific medical treatments you want in the event of an emergency. Only patients who have a serious illness, progressively declining chronic disease, or are near the end of life should have this form, which is completed by a physician or nurse practitioner. A POLST form does not replace an AD, but is complementary.

Research shows that advance care planning has many benefits for patients, their loved ones, and care providers.

Decisions about your health, medical care, and what you want to happen in the future are deeply personal decisions based on your values, preferences, needs, and beliefs. It is essential to identify what is important to you and communicate that to loved ones and care providers. Conversations focused on your needs and wishes can unburden your family and medical providers from having to guess what you need and enable them to focus on making happen what you want.

Sources of Additional Help:
Websites:
http://theconverstionproject.org (The Conversation Starter Toolkit);
https://www.acpdecisions.org; http://www.cdc.gov/aging/advancecareplanning.

Books:
A Better Way of Dying by Jeanne Fitzpatrick, MD, and Eileen Fitzpatrick, JD, London, UK, Penguin Books, 2010; *Advance Care Planning: Communicating About Matters of Life and Death* by Leah Rogers and Susana McCune, New York, NY, Springer Publishing Company,2013; *Wishes to Die For: Expanding Upon Doing Less in Advance Directives* by Kevin J. Haselhorst, MD, Scottsdale, AZ, Kevin J. Haselhorst PC, 2015.

CareNotes:
Advance Medical Directives: What You Need to Know by Rev. Lynn A. Burgess, MDiv, BCC; *Embracing Hospice: Living as Death Approaches* by Mary Kendrick Moore; *End-of-Life Concerns: A Guide for Families* by Rev. Daniel H. Grossoehme, BCC; *Including Your Family in Your Healthcare Decisions* by Mary Lynne Knighten; Using Palliative Care Well by Dick Sparks, C.S.P.;
When a Loved One's Care Decisions Are in Your Hands by Alice Camille, St. Meinrad, IN, Abbey Press Publications.

About the Author
Mary Lynne Knighten is an international speaker and published author on the topics of patient- and family-centered care, leadership, and whole-person health.