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Tagline

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Balancing Treatment Decisions for Patients at the End of Life

In a recent article published in the medical journal *Health Affairs,* palliative care physician Dr. Diane E. Meier recounts an experience with a cancer patient who had been living with non-small-cell lung cancer for six years. Because of the patient's overall good health and quality of life despite her diagnosis, Meier expressed surprise that the patient contacted her.

Explaining the patient's mindset, Meier says that "over the years [the patient] realized that her oncologist was hesistant to talk to her about the 'What-ifs?' of her cancer. What if this next treatment doesn't work? What if my disease progresses and I can no longer function the way I want to? Healthy and happy as [the patient] appeared, the uncertainty and the unknown were consuming her."

Although it would be months until the patient's cancer progressed to the point of comfort-only care, Meier was able to reassure her that all of her pain and symptoms at the end of life would be managed through palliative care, and that hospice was available to provide support for her and her family when the time came.

"Patients and families, especially those dealing with a progressive cancer, know that every life ends in death. They assume...that if the doctor recommends more tests and treatments, he thinks they will help in some way," Meier states. "Patients and families also assume that doctors will tell them when time is running out, what to expect, and how best to navigate these unknown and frightening waters. But many doctors don't do these things."

At times, physicians may feel that the only way to express their concern for their patients is to order additional interventions. Otherwise, they worry that patients will feel abandoned. "[T]he commitment to care and help is behind physicians' recommendations to their patients — recommendations firmly based on what they learned during their training," Meier explains.

Meier suggests that the training focus more on how to better communicate and relay "bad news" to patients and families. She also urges patients and families to initiate conversations about medical interventions with their physicians. *[See sidebar.]* Meier notes that it is important for doctors to know how to help patients and families make the best use of their remaining time together.

"With the right training and skills, doctors can honor that relationship throughout their patient's experience of illness, even and especially when disease-focused treatment is no longer beneficial," she concludes.

If You're Facing a Treatment Decision at the End of Life:

1. Is there a chance that medical intervention will be effective in achieving the goals you want from treatment (cure, comfort, etc.)?
2. What does your doctor think the benefits and drawbacks of the treatment will be?
3. Do you see your medical situation in a realistic way, even if it's not as positive as you'd hoped?
4. After learning about the benefits and drawbacks of the treatment, do you still want to move forward with intervention?

Adapted from "Evaluating a Patient's Request for Life-Prolonging Treatment: An Ethical Framework" published in the Journal of Medical Ethics.

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Information for Patients and Families

Saying Goodbye to Loved Ones at the End of Life

When a loved one is nearing the end of life, it can become increasingly difficult to address the "elephant in the room." Many people wonder how to start saying goodbye, or if they should.

When and how to say goodbye is a personal decision, and there is no right or wrong way to do it. Some people use this time to let go of past conflicts or resolve issues in their relationships with dying loved ones.

But how do you know when a conversation with a loved one will be your last? Because it's almost impossible to predict when your final conversation with a person at the end of life will be, say the important things early. However, even if your loved one is not alert, hearing remains until the end of life. You can continue to speak to the person in your normal tone of voice as if he or she were awake.

If you're struggling to know what to say or how to begin, some starting suggestions include:

- *"What I love most about you..."*
- *"What I will always remember..."*
- *"What I will miss most about you..."*
- *"What I learned from you..."*
- *"What I will cherish..."*

There may be pressure to say just the right thing, or to say something profound. But the important thing is to say what you feel and to not expect too much from yourself.

Some families worry that by talking about death, it will hasten their loved one's departure. Instead, think of your goodbye as a final gift to yourself and your loved one. Sharing what your loved one meant to you and how he or she impacted your life can help the person feel satisfied with a life well-lived.

Adapted from "When the Time Comes: A Caregiver's Guide" and from "Finding the Words (or Not) to Say Goodbye."

Online Guides to Completing Advance Directives

A key element in planning for the end of life is completing an advance directive. Different from a regular will, an advance directive includes documentation for a living will, naming a health care proxy, and organ donation.

A completed advance directive can help ensure that the care decisions you want made at the end of life take place, even if at that point you are unable to speak or make decisions for yourself. Interventions such as respirators, feeding tubes, and dialysis can all be covered in advance directive documents.

It can be overwhelming to try to figure out where to begin. Fortunately, there are multiple online resources that make the process easy to complete.

Caring Connections (www.caringinfo.org), a program of the National Hospice and Palliative Care Organization, provides advance directive forms and instructions for each state. The forms are short — only a few pages each — and do not take long to complete. Everplans (www.everplans.com), a website that securely stores information that families would need at the end of a loved one's life, also provides forms for advance directives as well as other important documents.

One of the more popular resources for advance directives is *Five Wishes* (fivewishesonline.agingwithdignity.org), a document written in everyday language that outlines multiple aspects of end-of-life care. In addition to covering medical treatment, the document also includes sections on "What I Want My Loved Ones to Know" and "How Comfortable I Want to Be." *Five Wishes* is currently only counted as a legal document in 42 states, but provides a beneficial outline regardless.

For more information about filling out and storing an advance directive, please call hospice.

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