

The Art of Goodbye: Exploring Health Concerns¹

Lynda Spence²

Introduction

This document is part of a series that addresses end-of-life concerns, entitled *The Art of Goodbye*.

Each of us has our own ideas about death and dying. Issues and questions about care at the end of life are as unique as the individual receiving care. Past experiences, age, and emotional states influence our ideas. The condition and culture of the patient and family, religion, spirituality, education, occupation, social class, friends, and personal preferences can affect end-of-life care. Sometimes decisions are made by the individual patient. At other times, the family and health care providers are involved. In either case, addressing each concern can be complicated.

Care at the End of Life

There are many considerations regarding end-of-life care that include:

- Right to refuse treatment
- Types of care:
 - Palliative
 - Hospice

Right to Refuse Treatment

The American Medical Association's Policy on Provision of Life-Sustaining Medical Treatment, found in the AMA Code of Medical Ethics, states, "Patients have a right to participate in decisions about their medical care. This fundamental principle of medical ethics holds true for all

types of medical treatments. Patients can refuse treatments even when such refusal is likely to result in death" (AMA, n.d.).

Palliative Care

"Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information, and choice" (National Hospice and Palliative Care Organization, n.d.).

Through the prevention and/or relief of suffering, palliative care provides essential assistance to the patient and family members who are coping with an extended, chronic, or terminal illness. Not all health care providers are experts in symptom management and emotional support. When palliative care is not in place, health care providers may:

- Fear that offering comfort care may suggest they have given up or failed
- Have difficulty saying that the illness cannot be cured
- Want to do everything to prolong life, regardless of the pain and suffering involved
- Be uncomfortable asking about patient's choices, including:
 - Hospital or home treatment
 - Breathing machines or feeding tubes

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2. Lynda Spence, Extension agent II; UF/IFAS Extension Marion County, Ocala, FL 34470-3615.

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Palliative care is comfort care that may include curative care.

When the goal is to heal, palliative care keeps the patient as comfortable as possible throughout the process. Curative care falls within the scope of palliative care. Not all palliative care is curative care or hospice care, but all hospice care is palliative. Hospice care focuses on the quality of life at the end of life.

Hospice Care

Hospice care shifts the focus of treatment from aggressive medical curative measures to medical comfort measures in the event of an incurable disease or condition. It is not intended to prolong life or hasten death.

Traditionally, Western medicine has concentrated on trying to cure patients; however, many health care professionals feel that approach does not address the realities of the medical world of today. Hospice care is an approach intended to help provide an optimal quality of life for patients and their families at the end of life.

Like palliative care, hospice care addresses the physical, psychological, social, and spiritual needs of the patient and family. It is provided by a multidisciplinary team of professionals, including doctors, home health nurses, hospice aides, volunteers, hospice workers, social workers, and clergy members. Physical therapists, massage therapists, dietitians, and pharmacists sometimes contribute to the collaborative effort to ensure the patient is as comfortable as possible at the end of life. Members of the hospice team create and implement a personalized plan that includes sharing useful information and providing both emotional and physical support.

There are four levels of hospice care:

- Routine care
- Continuous care
- Inpatient care
- Respite care

Routine Care

In routine care, family and loved ones serve as the primary care providers with the assistance of the hospice team. The patient can receive hospice services at:

- Home
- A home-like setting

- A nursing home
- An assisted living facility
- A hospice residential facility

Continuous Care

In continuous care, skilled nursing services are provided in the patient's place of residence. The hospice team helps during crisis periods.

Inpatient Care

Inpatient care is provided (at the determination of the physician) for a limited period of time when symptoms or crises that cannot be managed in the patient's residence arise. This kind of care can be provided in three locations:

- Hospital
- Medicare-approved nursing facility
- Hospice (freestanding inpatient facility)

Respite Care

Respite care is designed to give caregivers a rest. It can be provided in these locations:

- Hospital
- Medicare-approved nursing facility
- Hospice (freestanding inpatient facility)

Medicare Hospice Benefits

If a patient has Medicare Part A (Hospital Insurance) AND meets the following conditions, they can get hospice care:

- The hospice doctor and the patient's regular doctor certify that the patient is terminally ill (with a life expectancy of six months or less).
- Patient accepts palliative care instead of curative care.
- Patient signs a statement choosing hospice care instead of other Medicare-covered treatments for the terminal illness and related conditions.

According to Medicare, "Your hospice benefit covers your care, and you shouldn't have to go outside of hospice to get care (except in very rare situations). Once you choose hospice care, your hospice benefit should cover everything you need" (Medicare, n.d.). To learn more about Medicare coverage of hospice care, visit <https://www.medicare.gov/what-medicare-covers/part-a/how-hospice-works.html>.

Communicating about End-of-Life Care

The care we receive at the end of life should be informed by our preferences and our physician's knowledge of our preferences. Therefore, communication with our physician is of the utmost importance.

Thoughtful Conversations with Physicians

Circumstances change as our health declines, and these changes may further complicate matters. Therefore, when we communicate with physicians, we must be aware of the diagnosis, prognosis, and goals of care in order to frame our preferences (Pennypacker, 2014).

Diagnosis

The physician(s) will arrive at a determination of the cause or nature of a problem or situation and should explain it so you know what the diagnosis is and can make informed decisions. Do not be afraid to ask for clarification until you are satisfied. One way to know that you have fully understood what was said is to offer the explanation in your own words. If you can properly explain it, then you comprehend it.

Prognosis

Ask the physician to explain the most common course for someone with this medical diagnosis. The patient or loved one can pose open-ended questions such as:

- “Where do you think this is going?”
- “How have you handled similar situations in the past?”
- “Can you give me an example of a marker in time when I might ask that my medical treatment offer comfort, rather than prolong my life?”

We need to know the whole story to make educated decisions. For example, if a patient learns that a potentially risky procedure may result in hospitalization for the next six out of eight days, have a low survival rate, and only serve to prolong life for a matter of days, that particular patient may make a different decision whether to go forward with the procedure.

Goals of Care

Goals of care should be developed after thoughtful consideration of multiple questions, such as:

- How much medical intervention is the patient willing to undergo to gain more time?

- What are the patient's biggest fears?
- What functional abilities could the patient not imagine living without?
- What are other considerations as the condition worsens?
- How much information should be shared?
- How much would the patient want family members to know about their priorities and wishes?

When a Patient or Caregiver Takes the Lead

If a physician does not initiate the conversation, we may hold back, unsure of the best way to initiate the conversation. To that end, V. J. Periyakoil, MD, Director of Palliative Care Education and Training at Stanford University, developed a letter to clarify key issues (Periyakoil, n.d.). It can also serve as a conversation starter or guide. The letter is provided on pages 4 and 5, and can also be found at <http://med.stanford.edu/content/dam/sm/letter/documents/Letter-English.pdf>. For starters, take time to read and reflect on the contents. You can fill it out at a later date after you have had time to absorb the contents.



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Dear Doctor _____ (My doctor's name)

RE: What Matters Most to Me at the End of My Life:

I have been reading and thinking about end-of-life issues lately. I realize how important it is that I communicate my wishes to you and my family. I know that you are very busy. You may find it awkward to talk to me about my end-of-life wishes or you may feel that it is too early for me to have this conversation, so I am writing this letter to clarify what matters most to me.

_____ (My name)

What Matters Most to Me: *Examples: being at home, doing gardening, going to church, playing with my grandchildren*

My important future life milestones: *Examples: my 10th wedding anniversary, my grandson's high school graduation, birth of my granddaughter*

Here is how we prefer to handle bad news in my family: *Examples: we talk openly about it, we shield the children from it, we do not like to talk about it, we do not tell the patient*

Here is how we make medical decisions in our family: *Examples: I make the decision myself, my entire family has to agree on major decisions about me, my daughter who is a nurse makes the decisions, etc.*

Here is who I want making medical decisions for me when I am not able to make my own decisions:

1. Name: _____

Contact Information: _____

2. Name: _____

Contact Information: _____

3. Name: _____

Contact Information: _____

What I DO NOT want at the end of my life:

- , I do not want to be on a breathing machine.
- , I do not want artificial liquid feeding.
- , I do not want dialysis.
- , I do not want to spend my last days in a hospital.
- , I do not want to die at home.
- , Other _____

What I DO WANT at the end of life:

- , I want to be pain-free.
- , I want to spend my last days in the hospital.
- , I want you to help me die gently and naturally.
- , I want to die at home.
- , I want hospice care.
- , Other _____

If my pain and distress are difficult to control, please sedate me (make me sleep with sleep medicines), even if this means that I may die sooner.

- , Yes
- , No

What to do when my family wants you to do something different than what I want for myself:

- , I am asking you to show them this letter and guide my family to follow my wishes.
- , I want you to override my wishes as my family knows best.

Other information you want to convey:

Please scan this letter into my medical records in a place where your colleagues can read and be guided by it. I thank you for listening to me now and for the future work you are about to do, guided by what matters most to me.

Your grateful patient,

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Conclusion

It is too early until it is too late is a sentiment understood by professionals who provide end-of-life care. In other words, delays or complete avoidance of planning can result in missed benefits that would improve the quality of life as well as end-of-life care.

Take time for self-reflection, convey your thoughts to your physician(s) and loved ones, especially your health care surrogate, and then put your preferences in writing. Make sure your physician and health care surrogate have an up-to-date copy.

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