

# The Missing Piece in End-of-Life Decision Making

By Tani Bahti, RN, CT, CHPN

*It was bad enough that Gary was feeling the pain of only just understanding that his beloved wife was imminently dying. His pain was further exacerbated by learning too late that his best intentions in providing care only created more discomfort and conflict for the love of his life.*

I witness this scenario every week. Perhaps I should be used to it, but despite my 33 years of working in end-of-life care and education, it still pains me to hear the familiar lament, “If I had only known.”

In these situations, no one alerts the patient and family to the signs that death was approaching. No one tells them that it was time to replace a push for treatment with a push for comfort care. No one explains the natural course of the disease and the dying process. No one tells them how to respond to the expected changes to assure comfort and obtain closure.

When facing the end of life, we are naturally scared. Our problem is that too many of our decisions are based on this fear, or on lack of information or misinformation, which often results in devastating physical, emotional and financial consequences for the patient and family alike.

We can and must do a better job.

The question is not if we are going to die, but how we are going to die, and therefore compassionate and honest education about the natural process of dying is critical to making difficult end-of-life decisions.

The recognition of the point at which our loved ones are coming to the natural end of life becomes obscured with the flurry of medical interventions. We often hold onto a belief that “more is better,” that technology always holds the promise of saving us from dying, even if for a little while. Quality of life is often sacrificed for the hope of quantity, and can inadvertently result in more discomfort or time in an intensive care unit. We have to ask whether we prolong living or prolong dying.

When the body is preparing for its final months, weeks and even hours, many natural processes kick in to promote comfort. When families understand the wisdom of the body as it works to protect itself, they usually make decisions that honor the process of shutting down to die.

There is ample research about how the body begins to shut down to die. We know that the use of artificial nutrition and hydration at the end of life can actually increase discomfort and even hasten dying through fluid overload, aspiration, or increasing tumor growth. We know that the natural and normal cause of death for a number of diseases is pneumonia, once considered ‘the old man’s friend.’ We know that physical pain is not a part of the dying process, but that if it is a part of the disease, it can be managed. We know that the dying process will usually lead to a coma, which allows the individuals to essentially “die in their sleep.”

Unfortunately, the dying process is rarely taught in medical and nursing schools and is a frightening mystery to the general public. This lack of knowledge contributes to our discomfort with end-of-life discussions.

Sometimes, it’s the discomfort of the healthcare professionals who believe that death is failure or that telling the truth is ‘taking away hope.’ It becomes easier to offer a treatment, however futile, seeking solace in the illusion that doing anything is better than facing the difficult emotions of patients and families when they are told that reversal or cure is no longer possible.

Sometimes it's the inability of the patient or family to let go, or their fear of the unknown that drives futile care. Sometimes it's the belief that by refusing treatment they are somehow declaring that it's okay for their loved ones to die.

It's not easy to talk about dying, but there is clear benefit. A study conducted at the Dana Farber Cancer Institute by the National Institute of Health and National Cancer Institute was released in 2009 and revealed that having the conversation about end-of-life issues results in less depression, improved satisfaction with informed decision-making, improved use of available resources and better quality of life and death.

My own experience is that people want to know what to expect. They want the best possible care and comfort for their loved ones. They just don't know that it's okay to ask and do not know what questions to ask to determine the best course of care.

It will take all of us to improve how we talk about and prepare for the end of life.

Healthcare personnel must improve their knowledge and communication about the dying process. The patient and family must understand the natural progression of a disease and benefit and burden of treatment options. They must ask more questions, matching the answers to their own goals and values. They must keep updating their personal definition of quality of life and document their wishes. We must all face the fact that ultimately, dying is not an option and how we talk about, prepare for and honor the dying process is our right and our responsibility.

Let's provide road maps and comfort on the final leg of our journey.

## **Important Questions for Yourself and Your Family When Making Treatment Decisions**

- Do I have the information I need to make this decision?
- Is fear or lack of information pushing me towards a particular decision?
- What am I most afraid of?
- What are my goals at this time in my life and will this treatment help me reach them?
- Am I making a treatment decision based on what I believe someone else wants me to do or what I really want to do? Have I sat down with that person to clarify what each of us want?
- Who or what is my source of strength and support and have I utilized that?
- If I have a limited life expectancy, how do I want to spend the time I have?
- What does fighting the good fight mean to me? Seeking aggressive treatment until the end or allowing a natural death?
- Have I completed my advance directives (Living Will and Medical Power of Attorney), which declare my wishes for the extent of medical treatment I wish to receive in the event I cannot speak for myself?
- Have I talked with my family and physician about my advance directives?
- Have I asked all my questions, expressed all my fears, and shared what I truly feel with my family and physician?
- Is the goal of this treatment to cure, prolong life or relieve symptoms?
- What is the best I can hope for with this treatment?
- What is the worst I should prepare for if this doesn't work?
- Is this a standard treatment or experimental? What are the chances for success in my particular case?
- How and when will I know it's working?
- How will this impact my daily living, comfort and/ or goals? What are the physical changes I may experience and how will you help me manage them?
- If I have side effects, how long might they last? What can be done to prevent or minimize them?
- Are there any potentially permanent side effects?
- Is this covered under my insurance? What will the cost be to me?
- Will I need extra help to manage at home, and if so, for how long?
- If I refuse this treatment, what can I expect to happen?
- If I refuse this treatment, will you still be my doctor?
- Is there a counselor, support group or someone I can talk to about this?
- Do you have material about this treatment that I can take home and review?
- Are there other ways to manage my disease and would you recommend them? Why or why not?

Although medicine doesn't have a crystal ball to know how you are going to respond to a particular treatment, it is important that you have enough information to make an informed decision. Consider your lifestyle, your beliefs, your goals and values. Consider your family, finances and spiritual beliefs. You always have the right to know and to choose.

*Tani Bahti is the founder of Passages – Support & Education in End of Life Issues  
[www.passageseducation.org](http://www.passageseducation.org),  
 and the author of Dying to Know – Straight Talk About Death & Dying. [www. bookaboutdying.com](http://www.bookaboutdying.com).*