

A CONSUMER'S PERSPECTIVE: 3 TIPS FOR HELPING YOUR CLIENTS THROUGH THE END OF LIFE

BY TRISH LAUB



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When our parents simultaneously had serious health conditions, my family had to navigate the medical system and the world of providing care on our own. During every step of the journey, from the initial crisis through the end of life, that experience brought to light what we needed to know—but didn't. We had to learn everything the hard way.

For example, when my mom was in the hospital for her first major medical crisis at the age of 90, we quickly learned that short-term acute care hospitals' business model is based on a seven-day stay. By day 17, we had overstayed our welcome, and the hospital staff wanted to discharge her. Mom had been admitted with eight life-threatening conditions and was therefore considered a "complex case." She was not a good fit for skilled nursing, and we knew that we could not provide the level of care she needed at home. Literally in passing, as the hospitalist was leaving my mom's room, she almost whispered, "Why don't you take her to an LTACH?" We had never heard that term, nor was the hospital social worker familiar with it, so we immediately Googled it. That was our introduction to an invaluable option for post-short-term acute care, which we would not have known about otherwise.

More discoveries were made throughout the journey, including the end of life process of each parent. That was a bit more challenging, as the end of life is a topic that few want to acknowledge, let alone discuss.

While reflecting on my journey, I expressed my insights in *Peaceful Endings, Guiding the Walk to the End of Life and Beyond*:

"In America we prepare for the beginning of life, the arrival of a new soul, a baby, with gender reveals, baby showers, excitement, and good wishes. Choices for the birthing process include everything from hospitals, facilities, and medical doctors to a home water birth with assistance from a midwife. Pain management options include medications and a doula to provide support and comfort prior, during, and after the birth. The phrase 'birth plan' is often used. We offer our love and time to do whatever is needed to welcome the new

baby and help the happy, but tired, new parents.

In stark contrast, we do our best to ignore the fact that every life ends. We are a culture that denies death and therefore its dignity.

What if we put the same energy and love into the ending of life, the ushering out of a soul, that we do into welcoming a soul? What if we embraced the process that results in a soul transitioning out of this life as we do birth? What if our goal was to ensure death its dignity?"

During the end of life process, no matter how foreseen and distant or imminent, a case manager can be an invaluable asset. Based on my experience, I know that the following are some of the ways a case manager can be helpful to their clients in regard to the end of life.

1) PROMOTE "PRE-EMPTIVE PREPAREDNESS," AS SOON AS POSSIBLE

People are reticent to plan for their end of life, as the process is highly personal and requires us to face our inevitable mortality, triggering fear and negativity. When end of life planning is viewed as being as much for those who care for the patient as it is to help the patient live their remaining days as they choose, it becomes a great gift. It provides a roadmap for the family and those who provide care for the patient and assists with a smooth transition for everyone, removing the stress of having to guess the wishes of the dying person. In addition, identifying the patient's end of life wishes before the medical crisis or end of life is imminent allows decisions to be made calmly, rationally, and without fear. When the patient discusses the plan with their loved ones, it removes their fear and anxiety over not knowing what to do and can start an open conversation. It is a gift of peace of mind for everyone.

The case manager can assist their client in several ways, such as:

- Encouraging them to gather all pertinent legal, medical, and financial information and organize it in an easily accessible and portable manner that can be kept up to date. This allows for assessing whether the necessary legal documents are in place for both providing dignified care and delivering end of life wishes.

- Understanding the estate planning terminology for potential representatives of the patient, while alive and after: power of attorney for healthcare decisions, durable power of attorney for financial and property, guardianship, conservatorship and executor/executrix or personal representative.
- Guiding the client in knowing what documents are critical to end of life planning: a last will and testament, power of attorney designations, trustee designations if applicable and advanced directives or a living will. *Five Wishes* can be a helpful resource.
- Assisting with having the hard conversations that are required to know the patient's values and both care and end of life wishes. A case manager can coach the family on having the conversation or speak directly with their loved ones.

2) UNDERSTAND PALLIATIVE AND HOSPICE CARE

I believe that palliative care and hospice care are among the most valuable, and yet misunderstood, services offered in the United States. Hospice care is likely one of the most underutilized services, as people wait too long to start it. I experienced that the medical staff and hospital social workers often were unaware of the existence of the services and their benefits. Few people truly understand that palliative care is *an umbrella of comfort and quality of life care under which hospice care falls*.

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The umbrella of palliative care begins at the diagnosis of chronic, life-limiting or life-threatening illness – in short, life-altering illness. The focus of palliative care is on the patient's and their family's holistic care. The providers are specialists in *treating the symptoms of many types of disease*, and therefore are an addition to the medical team. Palliative care is a valuable service even when a cure is the goal, providing an additional layer of support for the patient, caregivers and family.

When the life expectancy is 6 months or less and no further curative treatments are being pursued, hospice care services may be initiated. It offers end of life services with the objective of providing a dignified and comfortable death among family and friends *at home* unless a medical or hospice facility is necessary. If a patient improves and no longer needs hospice services, it can be discontinued. The patient can requalify for services if needed in the future.

Palliative care and hospice care teams include MDs, PAs, NPs, RNs, HHAs, and CNAs, pharmacists, social workers and chaplains. In addition, palliative care may offer therapists (PT, OT, ST) and child-life specialists. Hospice may include trained volunteers to provide respite care for the family.

Both services provide the management of physical and emotional symptoms and psychological support. Palliative care can assist with the clarification and coordination needed for decision-making, end of life planning, and referral to hospice. Hospice can additionally provide medications related to the terminal diagnosis, medical supplies and durable equipment; education on how to care for the patient; short-term inpatient care when pain or symptoms become too difficult to manage at home; support and assistance at the time of death and following; and bereavement counseling and care for surviving family and friends.

The biggest misconception about both services, especially hospice because it is usually provided in-home, is that they provide 24x7 caregivers. It is important for your clients to understand that neither service provides in-home caregivers. If a patient needs in-home care, they need to arrange for that additional help.

For both palliative and hospice care, a consultation can be requested by the patient's PCP or specialist, or the patient can make the request. The consultation is used to provide

information to the patient about the services and also for the provider to verify the patient's *eligibility* for their services based on their health status.

Palliative services are available at some hospitals, both as outpatient and inpatient, through outpatient clinics and as an in-home service. Hospice care is intended to be provided at home, although it may be administered in a hospice facility if the in-home environment is not suitable or pain management is not successful at home. It is recommended to find a hospice provider that either offers inpatient care or has a contract with a hospice that does. Many hospital social workers have recommendations for palliative care clinics and companies in their area.

The Joint Commission on Accreditation of Healthcare Organizations oversees the certification of palliative care programs in hospitals. The National Hospice and Palliative Care Organization is dedicated to leading and mobilizing social change for improved care at the end of life. Both organizations can provide helpful information on the selection of a provider. For more information, I recommend scheduling a consultation with both a local palliative and hospice service.

3) UNDERSTAND DEATH WITH DIGNITY

Death with dignity is currently legal in nine states. Whether or not it is available in the state in which your client resides, it is valuable to understand it accurately as some people may consider changing residency to qualify. Like palliative and hospice care, death with dignity is often misunderstood. Also referred to as *medical aid in dying*, death with dignity allows terminally ill adults to request and, after being deemed qualified and mentally capable, receive a prescription for medication that they may choose to take to bring about a peaceful death. It is not available to those diagnosed with any of the forms of dementia.

Conversations about it can be at minimum emotional and escalate to highly charged. In his article, "The Ten Facts About Medical Aid in Dying," Dr. Grube, a longtime medical school professor and National Medical Director for Compassion and Choices, said, "Language matters: medical aid in dying should not be called 'suicide,' or assisted suicide." He went on to say that, "Legally, in all jurisdictions where medical aid in dying is authorized, 'it is not suicide, homicide, euthanasia, or mercy killing.'"

It is consciously choosing to end your life once certain criteria have been met, such as functional limitations, to preserve dignity during the end of life process. Medical aid in dying does not involve suicidal tendencies or the desire not to live. It cannot be executed spontaneously but instead requires due diligence by multiple medical practitioners, under strict legal purview, and the legal prescription of medication prepared by a licensed pharmacist.

Surprisingly, approximately 30% of patients never take the medication. They either die of natural causes before the medication has been delivered or before their planned administration date, or they change their minds as they didn't experience the anticipated decline in quality of life and chose to die naturally. In essence, the program gave the patient the power to have control over their own end-of-life experience and to decide what that would be for themselves.

I would suggest contacting the American Clinicians Academy on Medical Aid in Dying or visiting the websites of Death with Dignity or Compassion & Choices.

Regardless of your client's choices during their end of life, the case manager can facilitate a positive experience for both the patient and their family by 1) promoting the creation of peaceful transition space, whether at home or in a residential or medical facility, and designed in accord with the client's wishes, which will provide your client and their family a reprieve from the chaos that too often accompanies the end of life and 2) encouraging the family to continue to care for their loved one, to touch them and to speak with them as hearing is the last sense to diminish.

Throughout the end of life process, the case manager can provide invaluable guidance via tips and resources, but most importantly, peace of mind when the journey is done. ■



Trish Laub is a writer and educator who uses the expertise she derived from the full-time care of her parents, for whom she delivered the care and end of life they desired. Her *Comfort in their Journey* book series provides the clear, concise, and accessible information that she wishes had been available to her. You can reach her via email at info@TrishLaub.com or by visiting her website at www.TrishLaub.com.