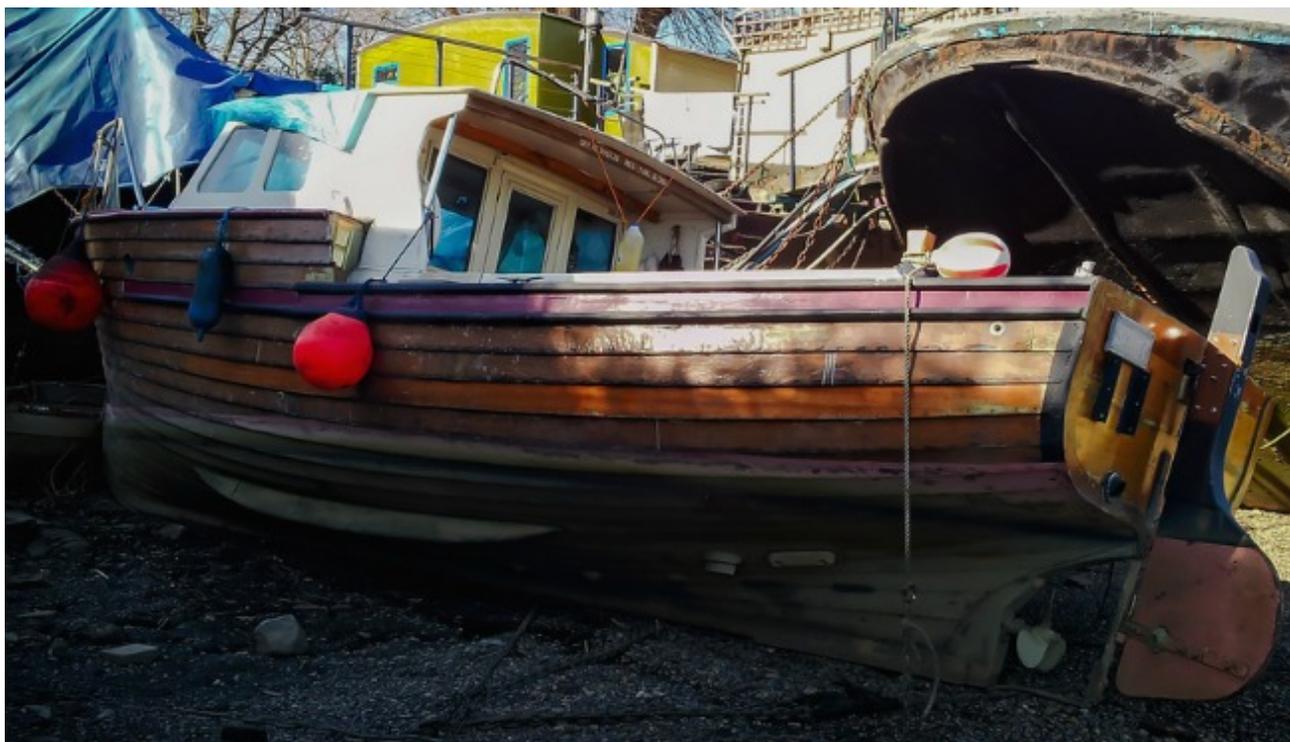


## Helping Make the Best of the End of Life



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Bettie Lewis was dying of metastatic cancer. Like many people coming to the end of life, she harbored two great fears: uncontrolled pain and abandonment. Though she was not completely comfortable, her pain was well controlled and causing her little distress. She had also developed confidence that her family and the team caring for her would remain with her to the end. She would not die alone. Yet she was deeply anxious that she would not survive long enough to see her soon-to-be-born grandson.

Fortunately she had sought care at a hospital with an outstanding palliative care program, including a team of nurses and nurse practitioners, physicians, social workers, chaplains, and volunteers who make it their mission to ensure the best possible care for patients and families facing life-ending illnesses. Though medicine had been unable to provide Lewis a cure, her healthcare team had not forgotten its core mission, which is to care.

### **The goal is not just to die well but to live well.**

Unsurprisingly, palliative care does not generate large amounts of revenue, nor is it the sort of service that many hospitals choose to advertise. But when it is done well, it can make a huge difference. Over one million Americans die every year, and in many parts of the country, over three-quarters die in a hospital or long-term care facility. While many say it might be better to die at home, for a majority, this simply is not what happens.

Palliative care enhances understanding, reduces suffering, and helps patients, families, and the healthcare team clarify goals. Because the focus is not on making the disease go away, it is possible to focus attention on living with it as well as possible. This bears repeating: the goal is not just to die well but to live well. Members of the team can talk openly with patients and families about what is happening and what lies ahead, helping them navigate these uncharted waters.

Without such expertise and commitment, some in healthcare can get dying very wrong. We can fail to ensure that patients and families understand the terminal nature of the situation. We can fail to relieve suffering, including pain, nausea, respiratory distress, and unrecognized depression. And we can fail to address conflicts over the goals of care - sometimes some family members push for comfort while others cling tightly to cure.

Patients, families, and health professionals all intend to do the right thing. We genuinely want to care for the gravely ill and do what we can to make their experience as comfortable and meaningful as possible. Many of us simply don't know how to do it. What should we do? What should we say? What should we avoid saying and doing? Left alone in a state of denial, many of us might cloak the whole experience in fear and embarrassment. But given the right support and guidance, we can shine.

One of the most important tasks is simply to listen. The patient will teach us what we need to know. But there are times when it helps to prime the pump with good questions. What is the worst thing about all of this? What are you afraid of? What are you hoping for? Is there anything you would like to talk about? Only if such concerns are addressed openly and honestly is there a realistic chance for genuine peace and healing.

When you talk with families who have experienced dying, one thing becomes crystal clear: they live with the experience the rest of their lives. They never forget it. So after a patient dies in uncontrolled pain, severe respiratory distress, or without truly understanding what is happening, family members continue to agonize long after the patient's suffering has ended. On the other hand, a good death can be an enduring source of comfort, bonding, and deep insight.

Talking about dying can be tricky. Some patients and families may initially interpret its mention as an indication that the care team has given up. This can be especially problematic when those involved belong to social and economic groups that have traditionally felt neglected or abandoned by the healthcare system. Their first instinct may be to think that the hospital is simply trying to reduce its costs by cutting back on therapy.

In some cases, the trust of patients and families is there from the start and never wavers. In other cases, trust must be earned. In both circumstances, however, the health professional's resources include curiosity and a sincere desire to learn. What are patients and families experiencing, what have they found meaningful, and what is working well and what isn't? Each time we learn such lessons, they can help us do a better job of caring for others.

Simply put, the key to caring for the dying is genuinely to care for the dying. Patients and families can tell when someone is merely going through the motions. Under such circumstances, saying even the perfect thing can ring hollow. By contrast, when care is genuine, patients and families will typically forgive any number of missteps. They may even find any number of imperfections quite endearing, so long as they are coated with real compassion.

In the case of Bettie Lewis, it soon became clear that her cancer had advanced too far. She would not survive long enough to welcome her unborn grandson into the world. In terms of her greatest wish - to see him - the situation seemed hopeless. The team could invite her to dictate a letter or record a message for him, but she would never be able to see him with her own eyes. Yet the team did not adopt an attitude of futility and resignation.

Instead they put their heads together and came up with an innovative proposal, to which the Lewises gave their enthusiastic consent. Mrs. Lewis could not leave her room, so they wheeled an ultrasound machine to her bedside. Her pregnant daughter lay down in the bed beside her. Then, as grandmother and mother held hands, a physician patiently introduced "Aiden" to them both. No formal request for an examination was submitted, no bill produced, and no interpretation rendered.

But for more than an hour, Lewis's eyes were glued to the screen. She witnessed her unborn grandson's heart beating, marveled at his exquisite fingers and toes, and delighted in his beautifully healthy body. She gazed transfixed on his face. Seeing Aiden not only made her day. It gave her the peace she desperately longed for. Her family and the health professionals with her will always treasure the experience.

The event was also photographed. Some day Aiden will have the opportunity to see his grandmother meeting him. In this way, her dying represented much more than the mere cessation of biological functions, but a lesson in love living on.