

HOSPICE & PALLIATIVE CARE

Reframing the conversation: When to seek help

By Dr. Ira Byock
For the Southern California
News Group

Dying is hard, but instead of making it easier, we keep getting distracted by sideline issues.

Physician-assisted suicide should be only a small part of the conversation.

Everyone I know wants to live as long and well as possible and then die gently, surrounded by people they know and love, and who love them.

A lot of what our nation needs to put in place to care well for people is readily available and affordable.

Mostly, however, people don't know when and how to ask for the services they need, including palliative and hospice care.

Multiple studies have shown that palliative care, including hospice, is often associated with people living longer. But I don't need research to tell me that because I know how hospice extended my cousin Edith's life.

Edith and her husband, Norman, were my parents' contemporaries and best friends and like an aunt and uncle to me. Our families spent lots of time together. Edith taught me to ride a bicycle, for which I am eternally grateful.

In late January 2004, at the age of 83, Edith underwent heart surgery. Things went well during surgery, but she had a difficult recovery, marked by prolonged heart failure, breathing difficulties, dangerous cardiac arrhythmias and profound depression.

She was in the hospital for weeks, much of the time in pain made worse by multiple medical procedures, and generally miserable.

Edith lost her appetite while in the hospital and, therefore, wasn't getting the calories or protein she needed to get stronger. She also was unable — or refused — to participate in physical therapy.

Edith and several of her immediate family members thought she was dying.

Edith's cardiologist disagreed. He explained that she merely had a shocked heart syndrome. It was unfortunate, he said, but it happens sometimes.

Multiple studies have shown that palliative care, including hospice, is often associated with people living longer.

While bothersome, he was sure she would eventually get better. With this assurance, the family acquiesced and prevailed upon Edith to go to a rehabilitation center.

The first one was awful and was too far from her daughter, so after a few weeks the family transferred Edith to another facility.

Things went from bad to worse for Edith. Clearly failing to thrive, the family readmitted Edith to the hospital. Now there was concern that she needed a feeding tube to supplement her nutrition.

Clinicians prescribed antidepressants, but Edith continued to decline.

I had been staying in touch with the family by phone but had not been part of decision-making conversations.

Edith's daughter-in-law Jenny, who is a nurse, called and asked me to weigh in. She described Edith as deteriorating in body and spirit. Her heart failure was stable, but she was losing weight, exceedingly weak, and getting weaker.

I asked her whether she would be surprised if Edith were to die within the next six months.

"Not at all. I would be surprised if she were alive in six months!" Jenny replied.

I suggested that we consider referring Edith to hospice, and Jenny thought it made sense.

Edith's general debility combined with her heart failure would make her eligible under Medicare regulations.

When her family approached Edith's cardiologist, he told them the idea was unheard of. When I subsequently called him, he initially said the same thing.



Dr. Ira Byock offers a personal perspective on palliative and hospice care.

However, when I asked him explicitly, he admitted that he wouldn't be shocked if she died in the next six months or even the next three months. He agreed that she had been declining in function and spirit.

I explained that the family was willing to care for her around the clock (including hiring nurses' aides to sit with her at night) and that the hospice program would send skilled nurses to weigh her and take her blood pressure and pulse, examine her with special attention to her breathing and edema, and help manage her medications, including her water pills and potassium.

A physical therapist from the hospice program would see her twice a week and would teach both Edith and her family strengthening exercises. This time, Edith's doctor reluctantly relented.

Once at home, Edith's depression lifted. She started eating and regaining weight.

She worked with the physical therapist and her nurses' aides and did her exercises faithfully.

Her improvement was slow,

but steady. Her heart failure gradually resolved. Her swelling subsided. Within three weeks she was up and around with a walker; within five weeks, she was feeling much better than she had felt before surgery. She graduated from hospice.

Rather than attending her funeral, as I feared I would be doing, I danced with Edith at a family wedding.

For me, Edith's experience epitomizes the connection between higher quality of life and survival.

She recovered her will to live and, thereafter, she recovered physically. Over the next 10 years Edith remained vibrant, sharp-witted, with her hearty, generous laugh until she died at 94 in her home, once again under hospice care, surrounded by family.

In 2011, shortly after we celebrated her ninetieth birthday, I visited Edith in the hospital.

She wasn't ill, but had been admitted simply to have the battery replaced in her implanted cardiac defibrillator. I asked her about her thoughts on hav-

ing been a hospice patient years earlier.

She said her cardiologist, whom she saw twice a year and liked very much, still thought I was crazy.

She laughed out loud when she told me that he teases her every time she comes in for her routine appointments.

"He's clueless! I wouldn't be here if it wasn't for you and hospice!" she joyfully exclaimed. Her children and I would make the same decision again.

Thankfully, nowadays those among us or our loved ones living with advanced heart failure are referred to hospice care more regularly and with far less resistance from their doctors. It makes sense because in living better it turns out we can also live longer.

Dr. Ira Byock, MD, is a palliative care physician and chief medical officer of the Providence Institute for Human Caring based in Torrance. This story is adapted from Dr. Byock's book, "The Best Care Possible," © Avery, 2013