



How Long Have I Got?

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Dave's story

Dave had a family history of heart disease. He had his first heart attack when he was 51. When he was 55 he had coronary bypass surgery. A year later he was found to have congestive heart failure. He seemed to respond well to his medication, but even so, he had increasing trouble with daily activities. He asked his physician how long he could expect to live, and was told he might reasonably expect one to two years of life. Shortly afterward Dave developed pneumonia, and his condition deteriorated quickly. He died about six weeks after the physician's estimate of life span. Dave's family felt that Dave, and they themselves, weren't able to value his last days because his life was so much shorter than he was led to expect.

Anna's story

Anna was a 73-year-old widow. She started having intense abdominal pain and her physician ordered tests. She was found to have an advanced and aggressive form of ovarian cancer. A few weeks later Anna met with an oncologist, who told her that the average life expectancy for someone in her circumstances was six months. She was not offered curative treatment. Anna returned home, began to give away her belongings, and cancelled a trip she had planned to visit her old home. Eight months later she was still alive. A palliative care physician found that this lifelong religious woman was distraught and convinced that God had forgotten her.

"How long have I got?" is an important question, one that most people facing life-limiting illness will think about and eventually ask. Answering the question as fully as possible reflects the science and art of providing care.

Both the asking and the answering may be intellectually and emotionally challenging for all of the people involved – patients, families and caregivers. The question likely means different things to different people, and the exchange of question and answer offers an opportunity for important communication between patient and caregiver.

Asking the question: The patient's perspective

There are plenty of reasons why "How long have I got?" is an important question for people. It may be less about "How much time is left?" and more about "How do I/we want to spend the time that remains?" Having a sense of remaining time provides an opportunity to rethink and prioritize how to spend this increasingly precious resource.

The question "How long have I got to live?" may take on a particular meaning for someone who is really hoping to live long enough to make it to a special event – a family reunion, a wedding anniversary, a graduation, the birth of a child. The response to "How long?" may drive a personal agenda to deal with business matters, to write a will, or to address personal relationships. It may involve reconnecting with neglected friends or families, or communicating important messages previously left unspoken. Expressed or unexpressed, "How long?" reflects profound human emotions – longing, fear, sadness, hope...

Answering the question: The caregiver's perspective

When doctors or other members of the health care team are asked "How long have I got to live?" their response may be less about an accurate prediction of survival and more about offering to provide care

response may be less about an accurate prediction of survival and more about offering to provide care that is trustworthy and compassionate. Caregivers' reactions will encompass a range of responses.

A prognosis is a prediction about the course a disease will take for a particular person. It is an age-old expectation people have of their physicians. Interestingly, until medical treatments became more effective over the last century, the main reasons for consulting a physician were to seek a diagnosis ("*What's wrong with me, Doctor?*") and to seek a prognosis ("*How long do you think this will last?*" or "*How long do I have to live, Doctor?*").

A number of tools have been developed to help predict survival, but none of the tools can predict with certainty. In addition to the knowledge, tools and experiences that doctors bring to the work of providing a prognosis, they, like their patients, have expectations, hopes and biases. These all influence their predictions about someone's survival. For example, they may have a well-intentioned desire not to overwhelm a patient or to take away hope, and so they may be overly-optimistic in their predictions.

Providing a prognosis

There is much uncertainty involved in developing a prognosis, and this can have an impact on patients and families. If death occurs sooner than predicted, they may feel they were robbed of valuable time they had hoped for and expected. Had they known time would be so short, they might have decided against difficult treatments and opted for earlier palliative care. They might have made it a priority to take on tasks of closure, such as making a will, or having final visits with friends and relatives.

If the person lives much longer than expected, the person or the family may be upset at having avoided doing certain things because they believed there was not enough time. If they had known they had enough time, they might have taken trips, or considered treatments that they did not pursue.

Currently, estimating the length and kind of survival a person might experience must take into account variations among patients, environments and diseases. It remains the case that some diseases progress rapidly in a predictable way; some diseases progress slowly in a predictable way; and some diseases are simply unpredictable. Understandably, estimates of length of survival tend to become more accurate as the end of life draws nearer.

Momentum of change

Of all the factors associated with the length of someone's survival, the most important single factor seems to be changes in the person's level of functioning, often called their performance status. The rate of decline in performance status will have a momentum, that is, a push for change that comes from the disease. This momentum of change can be used to estimate further decline. For example, when conditions decline significantly from week to week the person may have weeks of life left; big changes from day to day often indicate a prognosis measured in days.

While these sign posts may be helpful, it is important to remember that at the end of the day there is always uncertainty in predictions of this kind. There are frequent surprises – patients who live longer or shorter than expected. The health care team providing your care is in the best position to consider the many complex factors that influence the estimation of survival.

Dave's story continued

Dave's family asked to meet with his family physician to discuss their unhappiness with the physician's erroneous prediction. After much discussion, the family came to understand the many different factors involved in making a prediction of life span, and that the family physician's best guess was not just an attempt to give false hope. The family physician also became more aware of the unforeseen factors that can affect a prediction, and developed a greater appreciation of the importance of a prediction to the family of someone who is dying.

Anna's story continued

Anna's physician started treating her with an antidepressant. Anna's church was contacted and arranged visits by volunteers and spiritual counsellors. The visitors spent time with her, talked with her, and did small services such as combing her hair and bringing sweets she particularly liked. Anna became much less anxious and died in peace about two months later.

