



Terminal Illness: What does it mean?

Dr. Kenneth R. Stevens, Jr.

“My doctor tells me I’m terminal!” Mr. Jones blurted out to me in front of his wife. Mr. Jones had been referred to me because he had just been diagnosed with cancer in his right lung that had spread to his brain. Increasing headaches had caused him to see his doctor. CT scans of the brain showed two abnormal tumor masses in his brain, and further medical evaluation found the primary cancer in his lung that had spread to his brain.

I am a cancer specialist in radiation oncology. I have evaluated and, when appropriate, treated thousands of patients with cancer since 1967.

Mr. Jones was in his mid-fifties, married, with two married children. As I evaluated him, he did not outwardly appear ill. He was not having any breathing problems and, except for headaches, the tumors in his brain were not causing any neurological or mental problems. Yet, his doctor had told him and his wife that he was “terminal.”

What did his doctor mean? What does any doctor mean when informing a patient that he or she is terminal, or has a terminal condition?

Terminal means “the end,” and is a term used for many things: train terminal, computer terminal, etc. When used medically, terminal has an ominous and terrifying meaning. It means “this is the end of your life,” “your life is over,” “you have no hope of living much longer.”

How does a doctor come to the conclusion that a person is terminal or has a terminal illness?

Although most commonly used to refer to patients with cancer, “terminal” can also be used for other medical conditions. A patient’s terminal status can be dependent on treatment. A person with severe insulin-dependent diabetes mellitus could be considered terminal if they did not take insulin appropriately. However, with proper insulin treatment and diet, they can live a long time, even many decades. Patients with kidney failure requiring dialysis would die in a few days without dialysis; in that sense they may be considered terminal, but with dialysis they can live many years.

A close relative of mine was informed by her doctor that she had terminal pulmonary fibrosis and required supplemental oxygen. Upon hearing that ominous message, she notified her family of her diagnosis. All of her close family (siblings, children and grandchildren) traveled to be with her for one last time. It was quite a reunion. She, her husband, and family members were terribly distraught with her doctor’s medical opinion that she was terminal. “How long do I have, now that I am terminal?” she would ask me.

Today, four years after she received the “terminal” diagnosis, she still has terminal pulmonary fibrosis that requires constant supplemental oxygen and still lives in her home with her husband, who has his own significant medical problems. Family members and nurse’s aides spend time caring for her and her husband. She keeps speaking and focusing on her “terminal” illness—“How much longer do I have?”—yet she continues to enjoy the companionship of her large family, and they

appreciate that she has lived four years with a “terminal” illness.

I recently became acquainted with a man who told me the following story.

In August 2004, he had imaging studies done to evaluate him for kidney stones. Those imaging studies showed abnormalities in his liver. Further imaging studies showed 13 tumors in his liver and over 70 tumors throughout his lungs. Biopsy of his liver showed adenocarcinoma, a very advanced cancer. Specialized PET/CT scans showed his liver and lungs to “light up like a Christmas tree,” indicating widespread active cancer. His doctor told him, “You’re not going to last long.” He and his wife were told that he was terminal, that he would probably be dead in a month and a half and would not be alive for the next Christmas.

With that awful information from his doctors, he informed his employer, who changed his computer company management position to a less stressful one. Within two weeks of receiving the terminal diagnosis, he and his wife sold (at garage sales) or gave away an estimated \$20,000 of his tools and books in order that his wife would be unburdened of his stuff and to help prepare her for life without him. They sold his things for ten cents on the dollar and made arrangements for his burial plot in another state. They even contacted a realtor and almost sold their home, but three of their children still lived there.

He was puzzled because he did not feel ill from the liver or lung tumor abnormalities. He asked for clarification of the diagnosis. He thought, “There is no way I am going to die, I feel too good.”

Another biopsy of the liver was obtained. Seven different pathologists reviewed the tissue. Some pathologists questioned the accuracy of the original adenocarcinoma diagnosis, while others did not. The pathology slides and tissue were sent to a specialist in Boston, who said it was classic "epithelioid hemangioendothelioma" involving the patient's liver and lung. This correct non-terminal diagnosis occurred about a month after the original terminal diagnosis. The man consulted other cancer specialists about his new diagnosis. Some wanted to give him chemotherapy, and others were not certain what to do. Up to that point, he had not received cancer treatment of any kind.

In the past seven years he has had CT scans of his chest and abdomen every six months. The abnormalities in his liver and lungs are still present but have not changed in number or in size. He has continued to work for a computer company and misses the tools that he sold at a great discount or gave away in garage sales when he was informed he was "terminal."

After the original diagnosis, he and his wife made very hasty decisions that financially cost them dearly. Since they live in Oregon, that terminal diagnosis would have qualified him for doctor-prescribed suicide, a practice that is legal in both Oregon and Washington State. Tragically, he could have ended his life early and before he received the correct non-terminal diagnosis. In doing so, he and his family would have missed out on the past seven productive and healthy years, and even more years in the future.

In the mid 1970s, I had a patient who turned out to have a similar story. She was 30 years-old and had a large tumor in her liver that had spread to the central portion of her chest and was blocking the veins to her heart. She was also told that she had liver

cancer that had spread to her chest. She was told she did not have long to live. Yet, she lived over 20 years.

Twenty-three years ago, an 18-year-old college student was diagnosed with the most malignant type of brain cancer. I had the privilege of giving radiation treatments to his brain following removal of the cancer. Many doctors did not expect him to survive long, or if he survived they predicted that the tumor and treatments would significantly affect his brain function. However, he surprised them when he

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graduated from college, then attended and graduated from law school, passed the state bar exam, married, had two children, and was elected to his city's council. He lived a very successful and productive life for over 20 years from the time of his terminal diagnosis.

There are many reported instances of patients outliving the terminal diagnoses and prognoses of their doctors. Dr. Jerome Groopman, M.D., in his books *The Anatomy of Hope* and *Second Opinions*, describes many patients who have overcome and outlived their terminal diagnoses.

A few years ago, Art Buchwald, a humorist best known for his long-running column in *The Washington Post*, amazed himself and others by surviving five months in a hospice program with liver cancer and kidney failure. Well enough to leave the hospice,

he survived an additional 6 months before dying of kidney failure.

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So, what happened to Mr. Jones, the man I first told you about with the lung and brain tumors? After evaluating the extent of Mr. Jones' tumors, I offered radiation and chemotherapy to shrink the tumors. He accepted that recommendation and successfully completed the treatments with his tumors markedly decreased in size. He lived to spend two very productive years with his wife and children. They traveled together, and he lived to see the arrival of two additional grandchildren. Both he and his wife were very grateful for his prolonged and very functional life.

In talking with them, I recall that they—Oregon residents—did not understand why anyone would be interested in unnaturally shortening their life with doctor-prescribed suicide. They were totally opposed to its legalization.

My 44-year experience as a doctor for many thousands of patients with cancer has made me realize that it is very difficult to predict the life expectancy of a particular individual. Doctors can make generalized predictions regarding probability of death for a group of patients in a particular period of time, but that is a probability based on the group as a whole and not on specific individuals within the group. There is great variability in the course of an illness, particularly in those who are predicted to die many months from now.

Kenneth R. Stevens, Jr., M.D., is the former chair of the Dept. of Radiation Oncology, Oregon Health & Science University in Portland, and vice-president of Physicians for Compassionate Care Education Foundation (www.pcccef.org).

