Tom Petty’s advice on end of life

Suffering can almost always be avoided, with the doctor’s help

“Tom Petty invented pulmonary medicine as we know it today,” says Bernard Levine, MD, an Arizona pulmonologist.

“When he started... in the early 1960s... COPD was a disorder that nobody wanted to talk about or treat.”

Petty, who died in 2009, had COPD himself in later life. He was a pioneer in the use of medical oxygen. This article is condensed from COPD Digest.

Most patients with advanced COPD die of this common respiratory disease. They’re burdened by shortness of breath, chronic cough and mucus production, diminished activity, anxiety, depression, and despair. Many have asked me, their physician, about end-of-life matters.

I can empathize with these dying patients. I have faced death myself on four occasions after urgent open-heart surgery. I share my deep feelings with them. All physicians should do so when facing any dying patient. I’ve discussed end-of-life issues with patients and their families clearly, emphasizing that all life inevitably ends by design. I also stress that medical techniques can both postpone death and allow patients and their families to make it pleasant and meaningful.

Most COPD patients do not particularly fear death.

Accepting it as fact, they receive comfort and assistance from oxygen and other prescribed medications. Patients worry most about how they will die. They imagine themselves suffocating in anguish and delirium. This often panics them. Most do not want to spend the rest of their lives on a mechanical ventilator or have their death extended by it.

All patients — and their loved ones — must understand completely that suffering is rare and can almost always be avoided. As COPD progresses, carbon dioxide builds up as a normal consequence of impaired breathing. In fact, carbon dioxide retention has a calming, narcotizing effect.

TWO BIG MISTAKES

In some cases, doctors try to reduce elevated carbon dioxide levels by mechanical maneuvers or by stimulating the patient’s breathing with drugs. This is a big mistake. The kidneys compensate for the acid caused by carbon dioxide build-up, keeping acid levels in the normal range well into extreme limits of life.

Nor should doctors limit sedatives, tranquilizers, and painkillers for fear of suppressing respiration. This is another common mistake. Many doctors and nurses feel that these drugs will suppress the drive to breathe, and death will occur as a result. In fact, an excessive drive to breathe exists in most patients. This increases the work of breathing and creates respiratory distress. Thus, trying to keep carbon dioxide down to normal levels actually torments the patient.

Rest and normal sleep usually accompanies the skillful use of pharmacologic agents. Enjoyable food, ample fluids, and pleasant drink (including wine or substitutes) are perfectly appropriate.

Most patients can willingly face their impending death in the comfort of their home with their families, sometimes for months or even years. Hospice services help. They focus on comfort care, which should be the goal for all who serve these patients.

Institutional hospices serve mostly patients near death. Many patients deemed appropriate for hospice care live far beyond the previously limited six-month length of stay, just because they learn to adapt to their disease. One of my hospice patients even drove his car for two years, accompanied by his hospice worker. He was happy to participate in some pleasurable activity.

In COPD — as in other illnesses — death is not the enemy. The true enemies are fear of abandonment, loneliness, and pain and the anxiety that accompanies such fear. Proper medical care and loving attention can keep those enemies at bay.