

At Peace: “Is It Worth It?”

The question “Is it worth it?” gets to the crux of the issue of longevity versus quality of life. This often occurs when a person with a poor prognosis is facing grueling treatments or whose health is deteriorating and causing increasing discomfort. Most people are willing to sacrifice a short-term loss in quality of life for a chance at a much longer life. The variables of how much more life we can buy and at what cost are the critical issues. As we get closer to the end of our life expectancy, how we balance longevity against quality of life often changes. I thought developing a mnemonic device about quality of life could be helpful. I chose: AT PEACE. The AT PEACE questionnaire at the end of this article helps in the decision-making process. It identifies and clarifies priorities at the end of life and, in doing so, assists in the discussion about our choices with loved ones and health care providers.

Predicting how much longer someone with a terminal illness (not just cancer but processes such as end stage heart disease) is difficult. Physicians often overestimate the time remaining to offer patients and family hope. On the other hand, we all know people who were given “months to live” and who are still with us years later. This does not mean the disease process was cured. It usually means the progression of the disease slowed more than anticipated or they received new treatments or made lifestyle modifications that were effective.

The decision about what losses and side effects are acceptable is very individual. Changes that would have been deemed intolerable early in the decline of health may become acceptable as the disease progresses. For example, John had severe COPD (Chronic Obstructive Pulmonary Disease). He was an active man both professionally and socially with a large extended family. When first diagnosed, he mostly had to pace his activities to prevent shortness of breath. He would say, “If I ever become oxygen dependent, I would rather be dead.” When the time came that he needed continuous oxygen, John learned to live with it. In fact, he became the master of portable oxygen, BiPAP machines, and a host of other technologies and techniques to support his diminishing respiratory function. His ability to utilize assistive technologies allowed him to get around and stay connected. The steroid medications he used to keep his airways open caused a host of side effects. John learned how to minimize the side effects and to live with those he could not avoid. Until the very last days of his life, John was as active and connected as he could be despite the limitations of his condition. He never stopped trying to find another way of getting a little more time.

Wendy, on the other hand, who had a rare bile duct cancer being treated with photodynamic therapy (light activated chemotherapy) made different choices. One day she asked, “Is it worth it?” The response was, “When it is no longer worth it, you won’t have to ask.” Although the physicians did not offer any hope for a cure, they thought this new experimental treatment could “buy” her more time. She endured a tremendous amount of pain

and disability without complaint. Despite the toll on her quality of life, she was willing to pay the price for the possibility of living longer. When complications caused changes that required more personally invasive treatment, she decided it was no longer worth it. She had reached the tipping point between quality of life and longevity. She went into hospice the next day, stopped all treatments and medications, and died in just over a week.

The point of both these stories is to realize that the answer to “Is it worth It?” is unique to each individual, hard to predict, and will probably change over time. It is important to keep our mind and options open. If we are not sure about an intervention or treatment, we can start it and give ourselves permission to stop when we want. This is true of most interventions such as radiation, medications, and chemotherapy. Obviously, surgery is an all or nothing choice. Some interventions such as putting someone on a ventilator or using a feeding tube may be easier emotionally to start than discontinue. There are differing religious opinions about what must be done and what can be stopped once started. If that information is important, consult clergy experienced with end-of-life issues early in the process. Again, family and friends may have conflicting thoughts about what should or should not be done. Laying a foundation with others about the choices to be made may help diminish conflict. Ultimately, the decision rests with the patient or health care agent.

AT PEACE Questionnaire

A	How A nxious and A pprehensive are you as you look toward the end of your life? How much are you worried about losing control or suffering?
T	How important to you is having more T ime? Which is your priority: quantity of time or quality of life? Are there future events you would like to be able to attend?
P	How severe is your P ain? Does taking adequate medication for your pain create other problems such as lethargy or constipation?
E	Are you able to E at and drink sufficiently? Do you have an appetite or must you force yourself to eat? Are there swallowing or digestion issues that impact you eating?
A	Are you still A ble to do the things that are meaningful to you? (Such as walking, reading, socializing)
C	Are you experiencing symptoms that compromise your C omfort level? (Such as air hunger, nausea, sleep disturbances, bloating)
E	Are you still able to E njoy life despite whatever issues your health problem(s) and its treatment(s) produce?