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Lynn Monfort

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# Informed Consent

Lynn Monfort

My imagination staggers at the responsibility of medical professionals involved in caring for humanity at its least attractive, most obnoxious, and often final stages of life. Doctors and nurses have refined their bedside manners and become sensitive to patient needs. They strive to inform patients about their conditions and treatment options. In most classifications of illness and diagnosis, doctors know or recognize the problem and the appropriate series of responses. Their responses fix the situation, returning patients neatly to their lives. But not always. In my experience relationships between medical personnel and patients falls between adequate and promising.

Cancer, the silent killer, is one disease that challenges the stellar performance records of doctors and nurses. When the diagnosis is cancer, medical professionals can dramatically fail their patients and their profession. Cancer cures present patients with a more terrifying, more painful, more difficult and almost more destructive reality than the disease itself. Because cancer resists control, doctors and nurses seem to fear cancer, and that fear obstructs their ability to communicate with and educate their patients. A diagnosis so synonymous with death and destruction leaves patients charged with cancer's ugliness. Doctors try to gloss over the ugly side of treatment options and shift focus to the basic of life versus death. However, in my experience, doctors underestimate patients' ability to face the awful truth, so they don't even present it. In the moment of diagnosis even the most capable professionals have lacked the sensitivity, encouragement, optimism, and the courage to tell patients the entire truth. Truth enables heroes; truth can set the patient free to make logical choices, to give informed consent to survival.

Fear crouched in my doctor's announcement. He punctuated his verdict with long, sorrowful facial expressions that undermined my self-confidence. As he elaborated on my condition, I backed into a mental corner, confronted with a blurry picture of terrifying names, somberly pronounced, certain to deliver death. Before I drew another breath, blinked, or thought, the treatment names begin bombarding the tiny hopes that might otherwise have dug in long after the overwhelming announcement.

In speaking of cures my doctor glossed over each potential treatment option, and then, most amazing of all, he asked me to choose my own way out of that corner. Their limited advice? "Some people in your condition do this; some people in your condition do that; some do this and that. What do you want to do?" he asked.

Confronted with appendicitis, doctors won't offer the patient choices; they just fix it, remove it - finished, the end. Doctors set broken bones without the patient's input; they control and cure infections without options or the question, "What do you want to do"?

A professional admission, straight up, in front, that fighting cancer is a crap shoot that may be lost on the roll of the dice might at least allow patients a realistic basis from which to choose their own protocol of treatment. The future impact of significant information, often skipped over because the patient might run like a frightened child, extracts an enormous price in retrospect.

Consider that a mastectomy to treat breast cancer, for instance, not only destroys a woman's chest, but also can maim the arm associated with that breast. In the process of removing lymph nodes, major nerves get severed, destroying sensations to and from the arm. Post-surgical swelling changes the location of the arm in the socket; and often lymph edema, a painful ongoing condition where swelling disrupts the flow of lymph from the arm, invites endless infections. This surgery changes far more than a woman's profile; it is the negligent focus of the well-meaning professional who either doesn't know or doesn't relate the extra details. Why not inform a woman that removal of a breast removes the cancer and changes her

arm forever? She will pay for her continued life with long-term pain.

In treatment of prostate cancer the removal of the gland leaves impotence, urinary problems, and shortens the penis, all potentially devastating effects on the ego as well as the body. While doctors explain some events, they choose technical rather than emotional terms. In the moment of diagnosis and selecting treatment options, the choice of preserving body parts pales in a comparison between life and death. Physicians focus on the parts to be removed and emphasize that a breast or a few inches or other parts here and there are nothing compared to life. Calmly they describe physical treatments they have never experienced. The details they neglect to share are of post-surgical complications and the various horrors of the cancer treatment that create years of physical pain and cast a long shadow of sorrow over permanent physical changes.

At every turn in the process of cancer treatments the dire reality of what will happen is glossed over. "Radiation's easy; you don't even feel it," they say. In one way, that's true. The forty seconds spent alone under an enormous machine radiating your flesh is lonely, not painful. What you're not told is that for months afterward the radiated area blisters and peels over and over again; that a surgical scar in the radiation area may take years to finally heal; and that total physical exhaustion (never mentioned by the professionals) can begin anywhere from a week to a year after the forty-second sessions are over, and can last for another year.

"Chemotherapy may make you sick, but it doesn't last forever," they say. "Your hair may fall out, but it grows back." That sounds simple

enough when the professional explains it to you; but remember, they haven't lived through it. The white-smocked doctor or nurse isn't folded over the latrine waiting for violent spasms to stop. The professional isn't lying awake in the sweat-soaked bed, or freezing in the ninety-degree sunshine. The professional isn't exhausted, losing sleep, hair, weight, or the ability to think rationally and to have patience with endless minutes, hours, or months of pain.

Give the patient a clean statement. "You have cancer. Left alone it will kill you. Treatment, on the other hand, will maim you, shock you, hurt you, make you sick, and deeply challenge your ability to withstand pain. You *may well live, but live or die, you have cancer*, and absolutely nothing will ever be the same again. So, are you willing to give more than you can imagine in body parts and pain in exchange for life? Here's what we'll do for you. It could take years, and even if you eradicate it this time, it will always exist in your mind."

What's wrong with dealing fairly with the patient? With current bedside manner and treatment techniques, cancer patients who demand to know the truth must do their own library research; consult other patients and survivors; call the National Institutes of Cancer for the latest in protocols; and reach out to anyone and everyone else who can shed light on the "options" that box them into the corner. The patient must take the initiative to become informed, not only about the problem, but also about the half dozen possible cures and treatments in their endless combinations. When a patient survives the trauma of treatment and has banished cancer, doctors

remain always vigilant, always fearful, feeding the fear of the cancer patient who, try as he or she might, will never again escape the cloud of doubt. A sore arm might be cancer of the lymph system; a migraine might be a brain tumor; a period of listlessness might mean the cancer is gnawing away somewhere, defying detection. Every bump, lump, and ache gets prodded, poked, sliced, and tested by professionals checking in desperate pursuit of a missed cancer cell. It doesn't end just because the patient eventually feels better. The medical profession lurks, hovering, vigilant and nervous over their work and their patient, haunted by their lack of knowledge about and control over *the silent killer, and willing, if necessary, to paint a still blurry picture of treatment options next time.*

Rather than approaching cancer patients like foolish children and hiding all the ugly aspects of the potential cure, patients need the whole truth. Patient choices are best made as the result of complete education on disease and treatment options, including the scary parts. Only by informed consent are cancer patients able to choose their fight to win their own wars, battle by battle, month by month, in order to remain alive. Only with a true knowledge of what lies ahead can a patient fairly decide between body parts, pain, time spans, emotions, and life. Pour on the optimism and encouragement and sensitivity, but take up the courage to tell patients the whole truth. Informed consent changes lives forever, for the better.