

## Cancer care or cancer business ?

Nine years ago tonight heaven gained an angel and I lost my best friend, wife and dive buddy. Heaven called her, but cancer took her. Alison was diagnosed in early January and passed December 3<sup>rd</sup>.

We were so naïve and uninformed when our journey began that the outcome was likely pre-determined. The sad thing was that no matter how hard we tried we remained behind the curve. Her cancer was rare we were told, a hundred cases in a hundred years. There was no protocol; no one was working on it. Why would they? Too few cases and no money in it.

The cancer was metastasized so surgery wasn't an option; why we asked? Just the way it is; contrary to best practices. We had no idea and didn't really know how to argue our case. I never felt so impotent in my entire life. I was supposed to protect her, fix things and I could not, I failed.

Almost 60 days later I attended a large fundraising event in West Palm Beach and was struck by the notion that half the people were running in support of a cancer survivor and half the people were running in memory of someone who'd passed. Considering there were nearly fifteen thousand

people participating the emotional impact was numbing. Where was all this research money going and what was being done for the benefit of the patients?

President Nixon declared a “War on Cancer” in 1971. From 1971 to 2011 the National Cancer Institute (NCI) spent 90 billion dollars on research and treatment and that does not include monies spent by more than 260 private non-profit organizations supposedly raising money for research.

There is no doubt that we have saved some lives and extended the lives of many more, but we’ve not cured cancer. The race seems to be about converting cancer into a chronic condition to be managed. The cynic in me remarks that there is really no money in curing cancer, but there is tons of money to be made treating cancer, regardless of the impact on quality of life or what the patients may think. In fact there seems an effort to soft sell the impact of treatment protocols on the patient. I read an article recently that said in the last ten years we’ve increased survivability rates for certain lung cancers from 9-11 months to 24-36 months. On the surface that seems like a good thing, but a deeper examination of the numbers indicates that almost all of that time is spent in treatment and the treatment is particularly harsh.

I'll be the first to admit that I don't have a cure for cancer and I don't have a cure for cancer care, but a re-focusing on patient centered care in a real way seems to be appropriate.

I believe that when a person is diagnosed with cancer we should have a relatively brief cooling off period where in the patient/survivor is encouraged to process the diagnosis and they should be provided with information about the cancer they are dealing with. I have spoken with hundreds of cancer patients and I have never heard one story where the survivor said they were in an emotional state appropriate to making critical decisions about their long-term health care in that moment. We spend hundreds of thousands of dollars training doctors to treat medical conditions and almost zero dollars training them to deliver a diagnosis. I believe that the patient/survivor should recruit or be assigned an oncology navigator to listen at appointments and ask appropriate questions and that person should have only the patient's best interests in mind, not the hospital's, the doctor's or the research program's and if this person is a professional they should be paid by the health insurance provider. Asking a layperson to make complex decisions about treatment protocols for cancer is hardly appropriate. When

discussing treatment protocols doctors should be required to frankly discuss the effectiveness of any recommended regimen based on the patients' demographic. There should be a conversation about whether the treatment is intended as a cure or a management tool and finally there should be a conversation about the impact on quality of life. There should be financial transparency in the relationship. Patients and caregivers should be able to look around the nation to evaluate the cost of a particular treatment, the efficacy of any institution in delivering that treatment and whether the doctor is benefiting financially from the choice of drugs being administered. It's not widely discussed, but oncologists are allowed to be incentivized by drug companies for choosing one drug over another and in most cases doctors are allowed to purchase and resell chemotherapy drugs at a markup. There is nothing wrong with this arrangement, but it should be transparent.

The incidence of cancer diagnoses are increasing every year even though our national population has grown at a much slower rate in recent decades. The same is true of heart disease and diabetes. A reasonable person might ask if there are environmental or cultural reasons for this. There are many modalities of healthcare providers available to us and I suggest we stop considering them "new age mush". There is no doubt in the event of a

traumatic injury or pathogen based disease modern allopathic medicine has much to offer, but in the case of chronic conditions and auto-immune conditions we might want to seek guidance from elsewhere and improve the way we live our lives opposed to fixing our screw-ups after the fact when it may be too late. Traditional Chinese Medicine, homeopaths, naturopaths, chiropractors, acupuncture and acupressure practitioners have much to offer along with nutrition and exercise coaches if we take a longer view. In many cases these practitioners may help us be stronger and healthier while dealing with the effects of modern clinical medicine on the acute diseases of our time.